



# MONITORING AND MANAGING ILLNESS

FOR THOSE ON MEDICAL KETOGENIC DIETARY THERAPIES



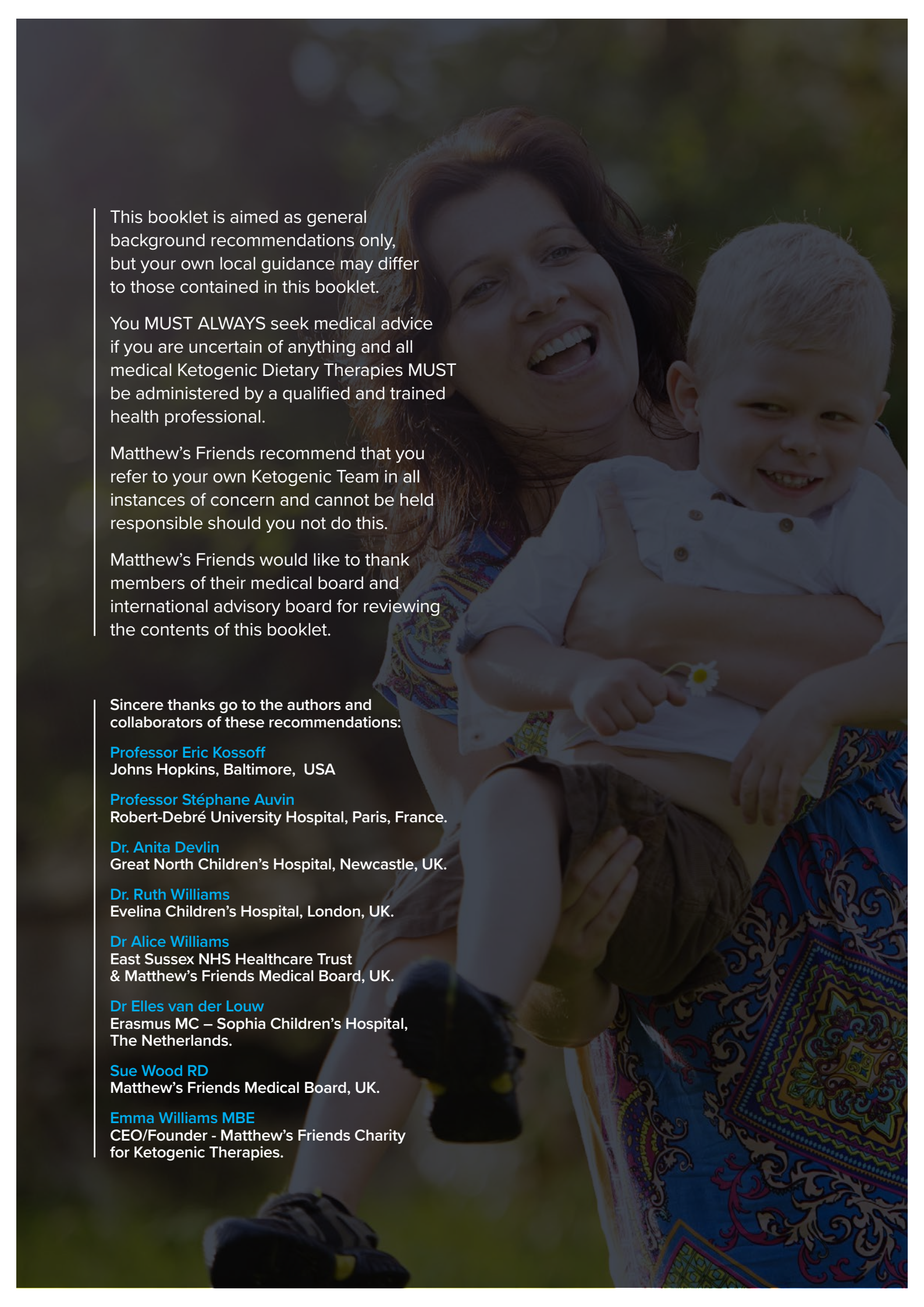
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A background image of a woman with long brown hair, smiling and holding a young child with blonde hair. The child is also smiling and holding a small white flower. They are outdoors, with green foliage in the background. The image is slightly faded to allow text to be read over it.

This booklet is aimed as general background recommendations only, but your own local guidance may differ to those contained in this booklet.

You **MUST ALWAYS** seek medical advice if you are uncertain of anything and all medical Ketogenic Dietary Therapies **MUST** be administered by a qualified and trained health professional.

Matthew's Friends recommend that you refer to your own Ketogenic Team in all instances of concern and cannot be held responsible should you not do this.

Matthew's Friends would like to thank members of their medical board and international advisory board for reviewing the contents of this booklet.

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# SECTION 1

## HOME MONITORING

**Ketogenic Dietary Therapy (KDT) is individualised to the patient and the dietary prescription may require frequent adjustment in the early months to achieve optimum effect. This should always be done under the supervision of your Ketogenic Team and your home monitoring information plays a key part in this.**

Monitoring can seem very time consuming in the early stages, particularly when you are spending so much time learning to weigh foods and cook new meals, however, it is KEY to getting the best from your KDT.

During the initial trial period you will be expected to keep in regular contact with your Ketogenic Team and supply them with the following details so that they can review the data to assess trends or make changes, adjustments to your diet prescription if required.

You should check your/your child's weight on a weekly basis on digital scales and keep daily records of:

1. Food intake, in terms of the amounts of carbohydrate, fat and protein portions eaten.
2. Seizures and any other symptoms or changes
3. Your home blood ketone and glucose tests (or urine ketone tests if you do these).

### HOME BLOOD TESTING FOR KETONES AND GLUCOSE

***N.B. Not every Ketogenic Centre tests in the same way, please be guided by your local team and what they require from you.***

Blood ketone and glucose levels may be tested on waking and before bed (or as directed) when introducing a KDT. The following gives you a guide as to acceptable levels and when you may need to take action or observe carefully for possible symptoms.

### WHAT LEVELS ARE ACCEPTABLE?

Blood ketones BETWEEN 2 - 6 mmol/l per litre (once full diet is established) are usually the optimal levels but individual cases may vary. It is advisable to avoid ketones consistently higher than 6 mmol/l per litre otherwise symptoms of hyperketosis could be seen (tiredness, irritability, facial flushing, vomiting and panting).

Adults do not tend to produce high levels of ketones as easily as children do.

Blood glucose generally stays within the normal range 3.5-6.5mmol/l. If the blood glucose drops to 2.5mmol/l or lower, you may observe symptoms of hypoglycemia such as tiredness, dizziness, sweating, pale, confused, feeling cold and clammy.

**What to do if Blood Ketones go too high OR Blood Glucose goes too low.**

#### SUMMARY:

Please consider contacting your keto team and taking action by giving extra carbohydrate when:

**Blood ketone levels consistently HIGHER than 6 mmol/l per litre**

OR

**Blood glucose is LOWER than 2.5 mmol/l per litre**

**Give one dose of 5g CHO - following are examples:**

- 50mls of pure fruit juice or
- 100mls of semi-skimmed milk or
- 5g of a prescribed carbohydrate supplement as directed by your medical team.

Please check blood levels again after 30 minutes and repeat the above treatment as necessary. Advise your Ketogenic Team when you have had to take such action and you must seek medical advice if ongoing.



## EFFECTS OF A KETOGENIC DIETARY THERAPY (KDT)

### The early days of initiation:

During the first week or so, it is normal to feel more tired, weak or even dizzy while your body adapts to the lower availability of carbohydrate and the need to burn fats as the primary fuel. In your child you may just notice that they are quieter and more tired than usual.

The main cause of these general 'flu-like' symptoms is an increased loss of water and salts from the body that shifts the body's normal balance during this early phase. This is temporary and soon settles as the body adapts to ketogenic fueling.

### What can you do?

- It's important to drink plenty of water and sugar free fluids.
- There may be some benefit from adding sea salt to meals or including a drink of clear broth/soup or stock cube drink. However, this is not appropriate for all. Do check suitability with your Ketogenic Team
- For both adults and children, it's a good idea to allow for this phase by easing up on the normal activities of daily life and taking time to enable rest and relaxation as needed.

If after a couple of weeks, you or your child are not returning to normal or improved energy levels, please make sure you alert your Ketogenic Team to this.

### NOTE:

If you are on blood pressure medication or have kidney problems, please talk to your Ketogenic Team before adding sodium and potassium salts to your diet.



### CONSTIPATION:

Ketogenic Dietary Therapies can slow the transit of foods through the gastrointestinal system. The lower carbohydrate and cereal fibre content can also alter bowel function, particularly in the early stages.

- drink plenty of water and sugar free drinks.
- Incorporate low carbohydrate vegetables or berries into each meal to help with fibre intake. Vegetables such as asparagus, Jerusalem artichoke, leeks, broccoli, Brussels sprouts, cabbage, cauliflower and kale are particularly good sources of prebiotic fibres that stimulate the growth of favourable bacteria in the colon. These help to support the immune system and stabilise bowel function.
- Ground flaxseed can be a very helpful bowel regulator and is easily incorporated into ketogenic bread, porridge, muffins, soups and stews etc. It is very important to ensure that adequate fluids are taken when introducing or increasing flaxseed.
- If a laxative is required, these can be prescribed by your doctor.

## SECTION 1

# HOME MONITORING

### LOW BLOOD GLUCOSE (HYPOGLYCAEMIA)

During the early stages of KDT's there can be a greater risk of low blood glucose as levels fluctuate while the body is adapting to use fatty acids and ketones as an alternate fuel. Once established, the blood glucose tends to be maintained more steadily at the lower end of the normal range (3.5-6.5mmol/l). However please look out for the following that may indicate low blood glucose levels (hypoglycaemia):

- Symptoms of low blood glucose may include sweating, becoming cold and clammy, jittery, confused or aggressive.
- If you have blood testing strips, it is useful to check blood glucose levels and if below 2.5mmol/l treat immediately. See the previous Home Blood Testing page for guidance.

**If symptoms do not resolve seek local medical help. Please keep your Ketogenic Team informed about episodes of low blood glucose.**

### HIGH BLOOD KETONES (HYPERKETOSIS)

Occasionally ketone levels can become too high. This may occur in the early weeks of establishing treatment, during illness or after a change in the diet prescription.

- Signs of excess ketosis are rapid, panting breathing, increased heart rate, facial flushing, irritability, vomiting and unexpected tiredness.
- If you have blood testing strips, it is useful to check the blood ketone level when any of these symptoms arise. If level is noticeably higher than previous readings or great than 6mmol/l and you are noticing any of the above symptoms, treat immediately. See the previous Home Blood Testing page for guidance.
- If excess ketosis occurs during the first two weeks of starting the diet, please ensure that you are giving the full quota of prescribed carbohydrate choices. It may be necessary to increase these slightly if you have recurrent episodes of excess ketosis.

Please keep your Ketogenic Team informed about episodes of high blood ketones.

### LOW BLOOD KETONES

Once ketosis has been established, blood levels can easily vary but the following may explain a sudden or persistent drop:

- Imminent onset of an illness such as a cold or tummy bug.
- If extra carbohydrate has been given in food or medication.
- After strenuous exercise such as football or swimming (extra ketogenic snacks may be required before or immediately after exercise. Please speak to your dietitian).
- Steroid medication (inform your Ketogenic Team).
- Other reasons such as hormonal changes.



#### NOTE:

**When using urine ketone strips please keep in mind the following:**

1. These strips 'expire' after a few months in an open container so readings may not be as reliable after this time. Make sure you replace them regularly.
2. The concentration of ketones in the urine will be influenced by the amount of fluid that has been consumed.
3. Urine ketones will also reflect what a person has eaten over the previous 6-12 hours, so are not as accurate as blood ketones.

## SECTION 2

# MANAGING ILLNESS AT HOME ON A KETOGENIC DIETARY THERAPY

Everyday colds, flu and tummy bugs may come along and upset the ketogenic control. You may notice blood glucose levels rise and ketone levels drop just before any illness develops. You may also notice more seizures and associated symptoms. This is quite common and should resolve once recovered from any illness. Please follow the basic guidance below BUT if you have any concerns, please speak to your Ketogenic Team.

### VOMITING AND DIARRHOEA

- Only water and clear sugar free fluids should be drunk until the vomiting has settled. It is extremely important to maintain an adequate fluid intake at this time, so drinks should be little and often as tolerated.
- Watch carefully for signs of low blood sugar or excess ketosis during this time.
- If the symptoms continue for over 24 hours then a product such as Dioralyte should be used, as this will replenish the body's electrolyte levels.
- When vomiting has stopped, please re-introduce the diet slowly. You may like to start with half portions of a meal replacement keto-shake or a ketogenic soup. This may need to be initially diluted with water or Dioralyte if there are problems with tolerance due to continued diarrhoea. In the initial stages of recovery, it does not matter if all the prescribed food choices for the day are not consumed. However, it is essential to maintain an adequate fluid intake with water and sugar-free drinks.
- If a return to normal eating has not been achieved within two days, please contact your Ketogenic Team regarding food guidance.
- Please contact your GP or local medical team for general guidance about illness.



### HIGH TEMPERATURE

- Use Paracetamol or ibuprofen tablets (or equivalent sugar free suspensions) to lower temperature as normal.
- Maintain an adequate fluid intake by drinking water and sugar free fluids without restriction.
- Please contact your GP or local medical team for guidance if you are concerned.
- Any prescribed medication, such as antibiotics, should be sugar-free where possible. Please discuss with your doctor, pharmacist or ketogenic dietitian.

## SECTION 2

# MANAGING ILLNESS AT HOME ON A KETOGENIC DIET

### WORSENING SEIZURES

- It is not uncommon for seizures to become more intense during the initiation of a KDT. They may be shorter and sharper or you may even observe an increase in frequency. This initial phase does not determine the eventual outcome of the therapy.
- Please follow your emergency seizure treatment protocol as normal e.g. Midazolam, Clobazam etc.
- Check blood glucose and ketones regularly.
- Keep a detailed record of seizure types, time of day and any notable changes. Include all this information on your monitoring forms.
- Contact your Ketogenic Team if you have any concerns or queries.



### EMERGENCY OR PLANNED HOSPITAL ADMISSION

The hospital or the individual ward may have no prior experience of KDT's therefore it is important for you to be as prepared as you possibly can. Please take the ketogenic diet prescription, your information file, blood meter, blood monitoring strips and portable food scales to hospital with you. You may also be advised to take in supplies of any prescribed food products and favourite food items.

- Blood glucose and ketone levels should continue to be monitored twice daily or more frequently if required while unwell or during treatment.
- If intravenous fluids (IV) are required, a normal saline infusion is recommended instead of glucose/saline. However, episodes of glucose containing IV fluids may be required if glucose and ketone monitoring indicate low blood glucose or high blood ketone levels.
- Please also give the staff a copy of section 3 of these recommendations.

Please let your Ketogenic Team know as soon as you hear about any hospital admission so that they can contact the resident dietetic team for help and liaise with the ward team as required.



# SECTION 3

## THE KETOGENIC PATIENT IN HOSPITAL

**How to support children and adults already established on a Ketogenic Dietary Therapy presenting with incurrent illness or for elective procedures.**

### ADMISSION

**On admission, the patient or their carers will be able to supply:**

- Information about their specific ketogenic regime.
- Contact details for their ketogenic dietitian / hospital team.
- Blood glucose and ketone testing equipment (if they use this at home).

If you are unable to obtain individual guidance, the following background basics may be of help.



### MONITORING

**If the patient is unwell, it is recommended that the following biochemical indices are checked:**

- Full blood count, renal function, liver function, ammonia, bicarbonate, lactate, beta-hydroxybutyrate, urinalysis, capillary blood gases.
- Please check weight on admission.
- Test urine for ketones each time passed.
- Check blood glucose and ketones 4 hourly if unwell or nil by mouth, otherwise please follow the individuals normal testing routine.

### BLOOD GLUCOSE AND BLOOD KETONE LEVELS; WHEN TO TAKE ACTION?

Ketogenic Dietary Therapy tends to produce a very stable blood glucose profile at the mid/ low end of the normal range and patients may not show symptoms of hypoglycaemia at 2.5-3mmol/l.

#### PLEASE TAKE ACTION IF:

**1.** Blood glucose is 2.5mmol/l or below.

**2.** Symptomatic

5g of a prescribed carbohydrate supplement as directed by your medical team and retest the blood glucose in 15 minutes. Repeat as required.

#### • Patient is symptomatic of low blood glucose:

- Sweating
- Clammy
- Excessive vomiting
- Increased sleepiness or confusion
- Fast heart rate
- Fast breathing

#### PLEASE TAKE ACTION IF:

**1.** Blood ketones are 6mmol/l or above/

**2.** Symptomatic

Treat with 5g of a prescribed carbohydrate supplement as directed by your medical team.

5g of a prescribed carbohydrate supplement as directed by your medical team and retest the blood ketones in 30 minutes. Repeat as required.

#### • Patient is symptomatic of excess ketosis:

- Facial flushing
- Rapid panting breath
- Fast heart rate
- Increased sleepiness or confusion
- Excessive vomiting

## SECTION 3

# THE KETOGENIC PATIENT IN HOSPITAL

### MEDICATIONS AND IV SOLUTIONS

- Avoid carbohydrate containing medications. Please check with pharmacy if you are unsure of the sucrose, lactose, glycerol or corn/maize content of any new medications.
- Avoid carbohydrate containing intravenous (IV) solutions (unless managing hypoglycaemia). Use normal saline.
- If IV fluids are required following the treatment of hypoglycaemia or hyperketosis, use dextrose containing solutions 2.5% dex +0.45% NaCl at the appropriate rate to maintain blood glucose between 3 and 5 mmol/L and blood ketones less than 6mmol/l. Once blood glucose or ketones are stable, change the IV fluids to normal saline but continue to check blood glucose and ketones 2 hourly.
- Rehydrate with water or sugar free squash if tolerated orally. Dioralyte (3.5g CHO per sachet) or hospital equivalent (check CHO content) may be used if electrolyte replacement is required.
- As soon as possible, return back onto ketogenic diet.
- Please liaise with the specialist dietitian during this phase.



### MANAGEMENT GUIDELINES FOR THOSE ON KETOGENIC DIETARY THERAPIES UNDERGOING GENERAL ANAESTHETIC

The literature on KDT and general anaesthetic is scarce, with very little consensus on management.

The most comprehensive study undertaken so far suggests that carbohydrate-free solutions are safe and blood glucose remains stable throughout surgical procedures up to 1.5 hours. The most common effect noted in procedures lasting more than 3 hours was a significant decrease in pH, requiring IV bicarbonate. Current advice therefore suggests monitoring blood pH during procedures lasting more than 3 hours and administering IV bicarbonate where necessary. (Valencia et al, 2002; Epilepsia; vol 43, issue 5; p525).

1. Contact Ketogenic Team in advance before the planned procedure. Please record the weight.
2. Check all urine for ketones on dipstick from admission.
3. Obtain bloods for:
 

- FBC	- Renal function
- Bicarbonate	- Liver function
- Blood Gas	- Glucose
- Lactate	- B-hydroxybutyrate
4. Keep nil by mouth for normal recommended time period (6 hours food/milk – Clear fluids 2 hours).
5. Use normal saline as the preferred intravenous solution and continue with carbohydrate-free solution throughout anaesthetic (use either 0.9% sodium chloride solution or Hartman's solution).
6. If anaesthetic is likely to be greater than 3 hours duration, monitor blood gas (pH and bicarbonate), B-hydroxybutyrate and glucose and treat any hypoglycaemia or hyperketosis by giving an IV bolus of 10% dextrose and changing to IV dextrose 2.5%/0.45% saline solution. IV bicarbonate can be given if blood pH is <7.2.
7. Continue IV normal saline until oral fluids tolerated.
8. Re-introduce normal (ketogenic) diet as soon as possible.

## SECTION 3

# THE KETOGENIC PATIENT IN HOSPITAL

### KETOGENIC MEAL PROVISION

- A Ketogenic Dietary Therapy (KDT) is high in fat, low in carbohydrate and provides adequate protein.
- Each child or adult will have an individualized diet prescription and menu guidance. This will vary according to type of ketogenic regime and their individual nutrition requirements. See below for basic guidance\*. Please ask them about their individualised KDT prescription, whether they have an emergency keto-shake meal replacement recipe and the contact details for their ketogenic dietitian on admission.
- Standard hospital menu options are often unsuitable for KDT's due to the mixed ingredient nature of the items. *NOTE: A ketogenic meal does not normally include any ordinary bread, potato, rice, pasta or standard breakfast cereal, although a medium chain triglyceride (MCT) KDT may include small measured amounts.*
- **The basics of a KDT can be provided by:**
  - A cooked breakfast sent with extra butter and double cream (for drinks or to add to fruit).
  - Plain cooked meat or fish with no thickened sauces or crumb coating.
  - Vegetables (non-starchy) or salads with extra butter, cheese, and oily dressing or mayonnaise on the side.
  - Fruits (preferably berries) with double cream and sugar free jelly can be a useful addition.
  - Items can be weighed according to the individual prescription once at ward level.
  - Ideally the patient will bring in scales (weigh to 1g) if required and any special prescribed products they use.
  - Please ensure that the ingredients for the emergency keto-shake meal replacement are available in case it is required.

### KETOGENIC DIETARY THERAPIES: THE BASICS

Food type	Classical KD	MCT KD	Modified Ketogenic Diet regimes or Low Glycaemic Index Treatment
<b>Protein based foods</b> fish, meats, poultry, eggs, cheese	All foods weighed	All foods weighed	'Normal ' portions
<b>Fats &amp; Oils</b> Butter, vegetable oils Mayonnaise, double cream, MCT oil, Calogen, Liquigen, K-Quik	All foods weighed	All foods weighed + measured volume of MCT oil with each meal and snack	Generous amounts included in all meals and snacks. (May use portion guidance)
<b>Carbohydrate containing foods</b> Vegetables (non-starchy), salads, Fruits (mainly berries), nuts, seeds, double cream, cows' milk (if used).	All foods weighed	May be weighed or allowed in hand measured portions. Speak to parents about how this is managed at home.	Measured by weighing or using tablespoon measurements.
<b>Fluids</b> Water, sugar free squash, sugar free fizzy drinks tea, coffee ( use unsweetened almond or soya milk or double cream.	Unrestricted Sugar / carb free	Unrestricted Sugar / carb free	Unrestricted Sugar / carb free
<b>Vitamin, mineral &amp; trace element supplements</b>	Required	Required	Required





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