

KETOGENIC DIET: INPATIENT MANAGEMENT - CHW

PRACTICE GUIDELINE[®]

DOCUMENT SUMMARY/KEY POINTS

- The Ketogenic Diet (KD) is a medically supervised high-fat, adequate protein and low carbohydrate diet that is used to treat refractory epilepsy and a metabolic condition called Glucose transporter 1 (GLUT 1) deficiency syndrome.
- The majority of patients commence the KD as an outpatient, however in certain circumstances the KD is initiated in the hospital.
- There are different KD types. The Children's Hospital at Westmead (CHW) most commonly uses the Modified Atkins Diet (MAD) version of the KD.
- Commencing a KD requires collaboration between members of the KD team (dietitian, neurology clinical nurse consultant, and pharmacist, neurology team, nursing team) and the parents and patients.
- Maintaining a KD can be difficult. Parent and patient education is essential in achieving optimal effects. Education includes assisting the family to understand the principles of the diet, preparation/meal planning, providing the family with resources and follow-up appointments to check progress.

CHANGE SUMMARY

- N/A - new CHW document

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

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| Approved by: | SCHN Policy, Procedure and Guideline Committee | |
| Date Effective: | 1 st April 2016 | Review Period: 3 years |
| Team Leader: | Consultant | Area/Dept: Neurology CHW |

READ ACKNOWLEDGEMENT

- All CHW clinical staff responsible for decision-making regarding the commencement and management of the Ketogenic Diet should read and acknowledge they understand the contents of this document. This includes:
 - Nursing staff
 - Medical staff
 - Dietetic staff
 - Pharmacists

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Introduction

The KD is well recognised internationally and may be a successful treatment for eligible patients with refractory epilepsy or Glut 1 deficiency syndrome^{1,2}. Up to 70% of children with epilepsy could have their seizures controlled with anti-epileptic drugs (AEDs)³. For some children who continue to have seizures, the retrospective and prospective studies¹ have shown a greater than 50% reduction in seizures in children with refractory epilepsy placed on the KD, and many became seizure free after only 3 months. The exact mechanism of action still remains unclear, though it is suggested that the high fat and low carbohydrate content of the KD mimics the body's biochemical response to starvation, relying on fat rather than carbohydrates for energy⁴.

Definition

The KD was first used in 1921 when it was noted that seizures reduced when people with epilepsy didn't eat normally or when they were fasting^{4,5}. This fasting state mimicked a similar metabolic state, which we aim to achieve with the strictly controlled, medically supervised KD^{5,6}. The KD is very high in fat (such as butter, margarine, cream and oil) and low in carbohydrate⁷. Regular monitoring helps to make sure there is a correct balance of dietary fat and carbohydrate to have the positive effect in reducing seizures⁷.

Ketones are produced by the body from the breakdown of fats^{8,9,10}. Ketones are used by the brain and muscles as a source of energy instead of glucose from carbohydrates^{8,9,10}.

Ketones can be measured in the urine and these levels can help us monitor that the diet is producing ketones^{7,8,10}. Although the diet is high in fat, total energy intake is balanced and monitored to allow for normal weight and growth^{8,9}. A child on the KD should not put on lots of weight.

Types of Ketogenic Diets

- Modified Atkins Diet (MAD)
- Classical Ketogenic Diet
- Medium Chain Triglyceride Diet (MCT)
- Modified MCT diet
- Low Glycaemic Index (GI) treatment for Epilepsy (LGIT)

Note: The neurology team at The Children's Hospital Westmead usually recommends the Modified Atkins Diet (MAD).

Indications for the Ketogenic Diet

Eligibility for the KD is mainly based on the child's underlying disorder^{10,11}. Collaboration with the family is essential to determine the child's normal dietary/food patterns, usual meal planning and what is age-appropriate. This information will help determine the most appropriate type of KD and compliance factors can also be anticipated.

Ketogenic Diet in the Hospital

The majority of patients commence the KD as an outpatient, however in certain circumstances the KD may be initiated in the hospital. Parent and patient education is essential to optimise compliance and to help achieve optimal seizure control. This includes providing the family with KD-specific information such as administration of medications (ideally sugar free or minimal carbohydrate content formulations), how to test urine for ketones and meal planning based on the child's nutritional requirements.

If a child is admitted and is on a KD, the Neurologist, Neurology CNC, Dietitian and Pharmacist must be contacted on admission. Advice will need to be sought from the treating Neurologist before prescribing new medications or IV fluids, which may contain dextrose/carbohydrate/sugars as this will influence the effectiveness of the KD. Medications must be sucrose, aspartame and sorbitol free to be compatible with KD.

Commencement of Ketogenic Diet Flowchart

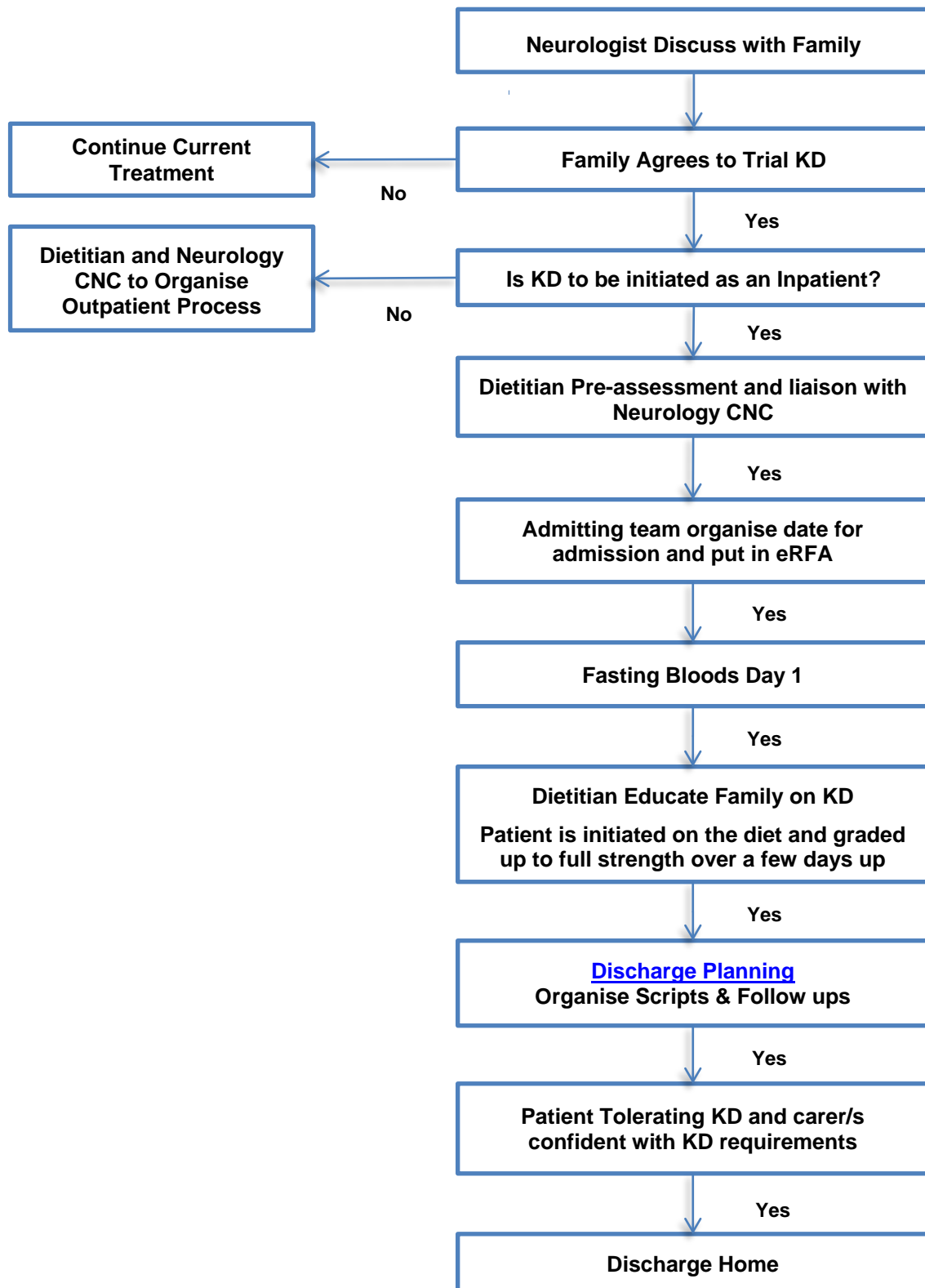


Figure 1: Commencement of Ketogenic Diet Flowchart

Nursing Responsibilities

- All urine tested for ketones, level documented in mmol/L on Fluid Balance Chart
- Record accurate intake of KD on Fluid Balance Chart (including what not eaten). Inform dietitian of concerns regarding ketone levels, BSL, KD diet strength or poor compliance of diet
- Liaise with medical officer and dietitian of any side effects of the KD diet (abdominal pain, diarrhoea, lethargy, nausea and vomiting)

Monitoring

Blood Sugar Level (BSL)

- Low BSL may occur during the initiation stages of the KD
- Unless clinically indicated, BSL's are usually monitored 1 hour post main meals until established on KD or as directed by the dietitian/neurology team
- Symptoms of hypoglycaemia include irritability, sweating, dizziness, shakiness, hunger or palpitations (rapid pulse)⁵

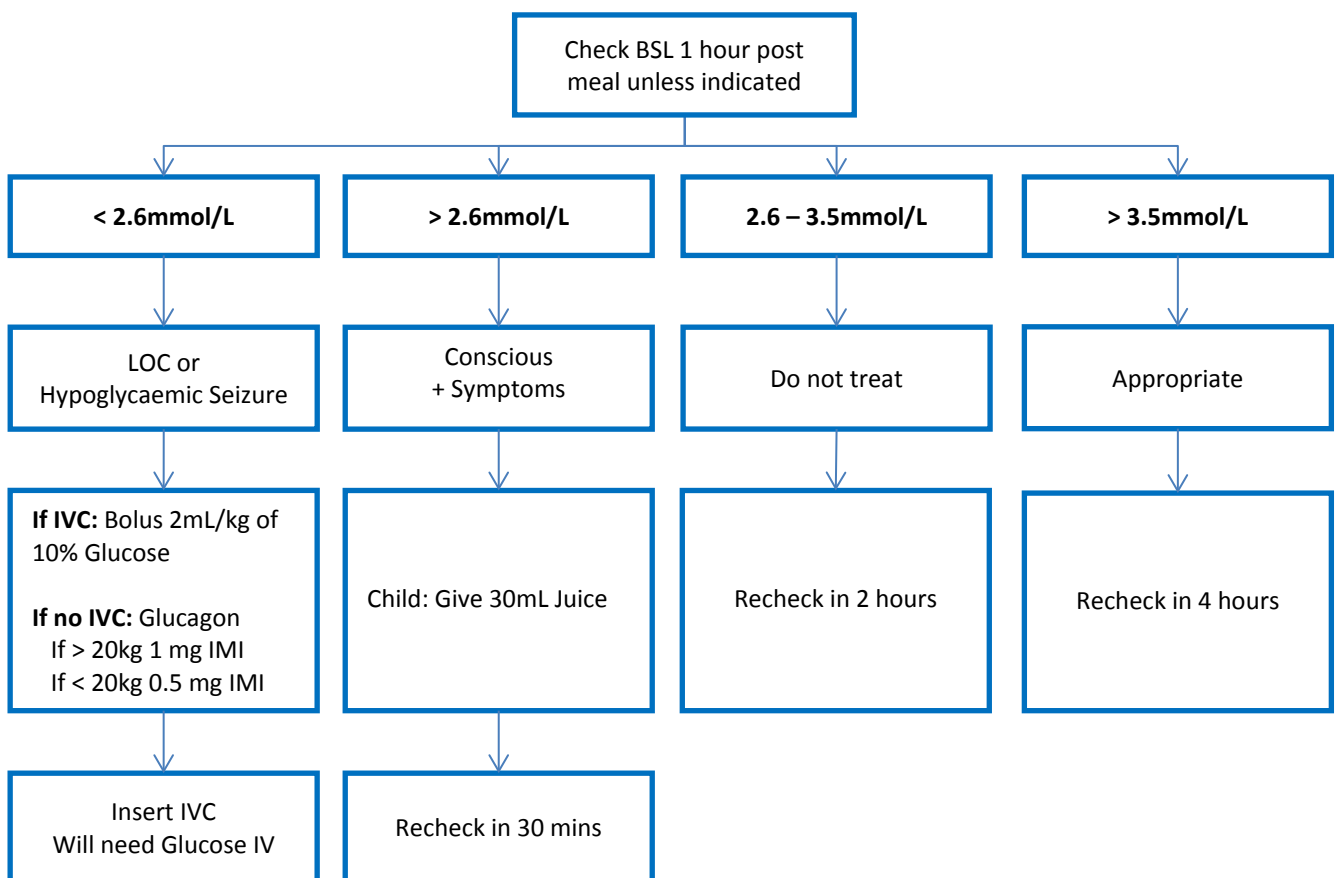


Figure 2: Flow chart of hypoglycaemic management

(Adapted from: [Hypoglycaemia on the Ketogenic Diet – SCH](#) Practice Guideline [No: 0/C/14:7003-01:00] July 2014)

Ketones

- Test urine with keto diastix, twice per day (morning/evening) **OR** if testing blood ketones (<12months of age), twice per day
- Record result as mmol/L on KD observation chart (urinary range 0-16mmol/L **OR** blood range 3.5-5.5mmol/L)⁵
- If 2 x consecutive readings of ketones at 16mmol/L **OR** >5.5mmol/L and symptomatic⁵ (food refusal, nausea, rapid shallow breathing, facial flushing, vomiting, excessive tiredness or lethargy and increased heart rate). Will need to be treated with 50mls ward stock juice or Carbplus from the formula room and inform the neurology team.

Dietitian Responsibilities

- Conduct full nutritional assessment
- Liaise with nursing staff/neurology team progress of the KD
- Provide education to parents/carers. Including diet trouble shooting, signs and symptoms of hypoglycaemia, ketosis and treatment
- Document alert on powerchart

Monitoring

- Review pre-KD bloods, consult with treating neurology team and consider starting a multi-vitamin if required
- Monitor side effects of the diet (abdominal pain, vomiting, lethargy, nausea or constipation)
- Ensure correct menu is sent to patient for meal selection.
- Monitor compliance with the diet

[\(See Clinical Nutrition Guidelines for Ketogenic Diets – Department of Nutrition and Dietetics\)](#)

Pharmacist Responsibilities

- Review current medications for carbohydrate content during admission
- Liaise with treating neurology team and recommend any changes or alternative preparations required to comply with KD requirements.

Medical Responsibilities

- Order fasting KD pre-diet blood tests (pre-set on powerchart)
- Re-chart medication if current medications non-compliant with the diet
- Liaise with the multidisciplinary team and patient's family daily to assess clinical progress and in preparing the family for discharge
- Liaise with dietitian and pharmacists for scripts prior to patient discharge

Discharge Planning

- Treating neurology team to arrange scripts. KD formulas, glucose/ketone diagnostic strips, and vitamins must be ordered on a prescription form. Certain KD formulas must be ordered on an authority script ([see appendix 1](#))
- Clinical Nurse Consultant to assist with discharge planning and routine follow up,
- Parents/carers provided with relevant team members contact details,
- Dietitian and multidisciplinary team to ensure parents/carers are confident in maintaining KD in the home setting,
- Follow up appointments to be confirmed with dietitian and the treating neurologist team.

Ketogenic Diet Resources

- [Ketogenic Diet Parent Information Sheet](#)
- The Charlie Foundation: <https://www.charlifoundation.org/>
- Matthews Friends: <http://www.matthewsfriends.org/>

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Appendix 1 – Prescribing for Ketogenic Diet

When commencing the KD you require a PBS script for ketocal and keto-diaistix prescribe by your paediatric neurologist or paediatrician.

Classical KD script requirements:

- 24 tins x **KetoCal** 4:1 unflavoured (Nutricia) - 5 repeats
- 2 x 50g **Keto-Diaistix** Glucose and ketone indicator urine diagnostic strips - 2 repeats
- 30 x 6g (VitaFlo) **Fruiti Vits** - 5 repeats
(**Authority** script required)

MAD script requirements:

- 7 x tins Vanilla **KetoCal** 4:1 (Nutricia) - 5 repeats
(**No** authority script required)
- 32 x 200ml **KetoCal** 4:1 LQ (Nutricia) tetra-packs - 5 repeats
- 2 x 50g **Keto-Diaistix** Glucose and ketone indicator urine diagnostic strips - 2 repeats
(**No** authority script required)
- 18 x 2 cartons of **Carbzero** (VitaFlo) 250mL - 5 repeats
(**No** authority script required)
- 30 x 6g (VitaFlo) **Fruiti Vits** - 5 repeats
(**Authority** script required)