KETOGENIC DIETARY THERAPY FOR CHILDREN WITH EPILEPSY

Canterbury District Health Board
Te Poari Hauora ō Waitaha

Charlene Tan-Smith
Paediatric Ketogenic Dietitian
Ketogenic Service Christchurch Hospital

Epilepsy

- Epilepsy is common and for many treatable
- Intractable or medical refractory epilepsy - ~30%
- For this group, besides exploration of other drug alternatives, we have to look at other options

- *“One who is confronted with the task of controlling seizures in a person with epilepsy grasps at any straw. When some 6-8 years ago, an osteopathic practitioner in Michigan stated that fasting would cure epilepsy, this seemed like a very frail straw…(but) in many patients there was freedom from seizures during fasting.”*

Lennox 1928

Overview

- Historical info on dietary treatment
- Variations of KG diet
- Basic physiological basis of diet
- Results/efficacy
- Side effects and complications
- Christchurch Hospital
  - Criteria for selection
- Medications
- Case studies

Historical

- Hippocrates – 5th century BC
  - Middle aged man cured of epilepsy by total abstinence of food and fluid
- Biblical times
  - Mark recounts Jesus curing an epileptic boy

  "this kind can come out by nothing but prayer and fasting"

The last 100 years

- Gulpa and Marie – 1911
- Dr Hugh Conklin and Bernarr McFadden
  - All diseases cured by diet and exercise
  - Prescribed fasting for 3 days to 3 weeks
- Geyelin – 1921 -> NY based Endo
- Wilder – 1921 -> MayoClinic
- Wealthy Family -> donation -> John’s Hopkins hospital

The last 100 years

- It is difficult to find hard data from that time, but some of the success rates (improvement, not freedom) were quoted as being as high as 50%

- 1938 – Merrit and Putnam discover Phenytoin…

> After 1938

more and more anticonvulsants became used over time… the diet went out of flavour

THE CHARLIE FOUNDATION
for Ketogenic Therapies

- Resurgence in use of diet in 1990's
- Jim Abraham

  ->The Charlie Foundation

Charlie Foundation
FOR KETOGENIC THERAPIES

THERAPIES LEARN AM I A CANDIDATE RECIPES STORE RESOURCES ABOUT

WHAT IS KETOSIS ?

AM I A CANDIDATE ?

FIND SUPPORT

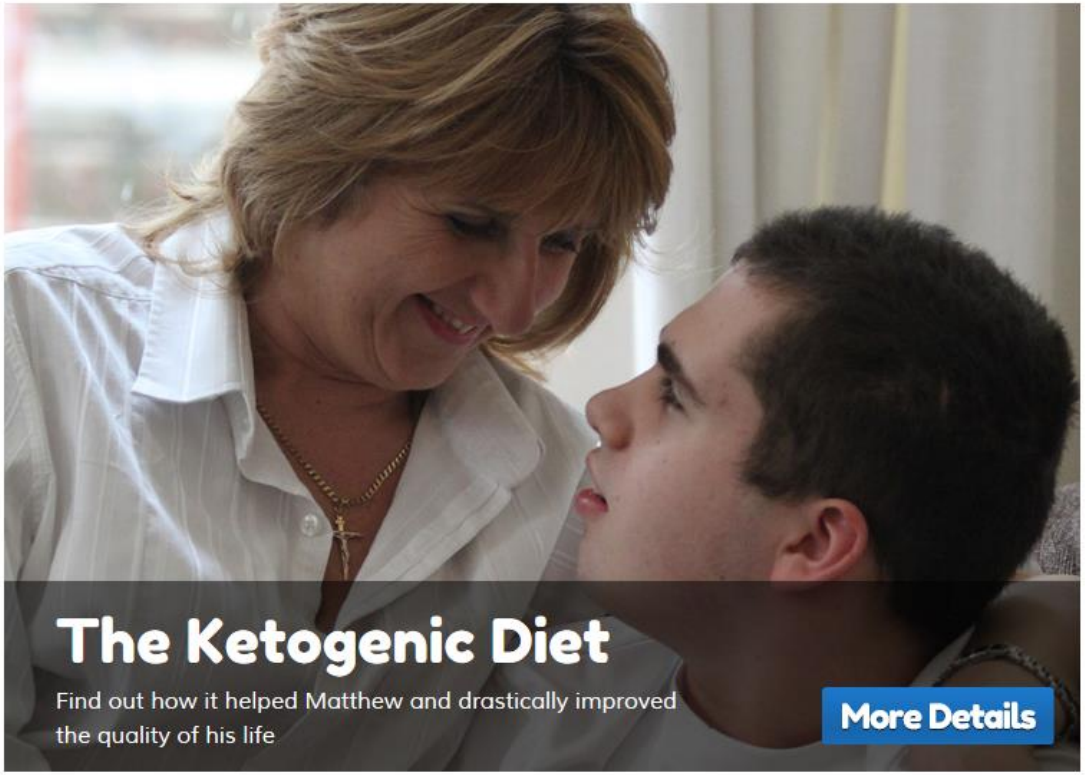
MATTHEWS FRIENDS
Ketogenic Dietary Therapies
Information • Training • Research • Support

friends family food

eat something yummy for money

Matthew's Friends KetoCollege

Donate with JustGiving



Matthew's Friends are a UK registered charity (since 2004) specialising exclusively in medical Ketogenic Dietary Therapies.

We support patients, families and professionals by providing information, training, research and grants to develop Ketogenic services and support systems for drug resistant (refractory) epilepsy as well as other neurological and metabolic disorders and emerging cancer types.

Our charity is supported by key medical experts in these fields so as to ensure the safety and efficacy of our information.

Please watch our introduction video by clicking here.

What is the Ketogenic Dietary Therapy?

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High fat, low carbohydrate and low protein diet

NOT a FAD Diet

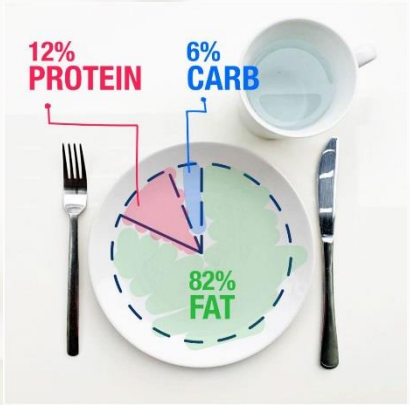
What is the Ketogenic Dietary Therapy?

High fat, low carbohydrate and low protein diet

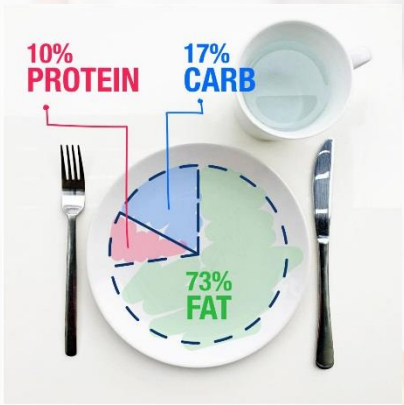
- Types of diet: "classic", MKD, MCT, LGIT, MAD
- Typical ratio of fat to CHO and protein is 3:1 to 4:1 (i.e. 85 – 92% Fat)

What is the Ketogenic Dietary Therapy?

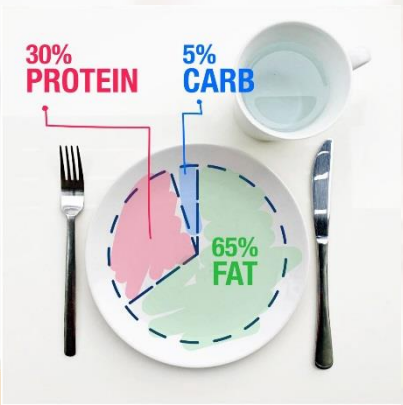
Modfied keto



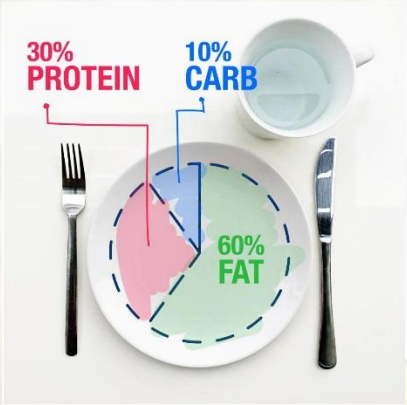
MCT



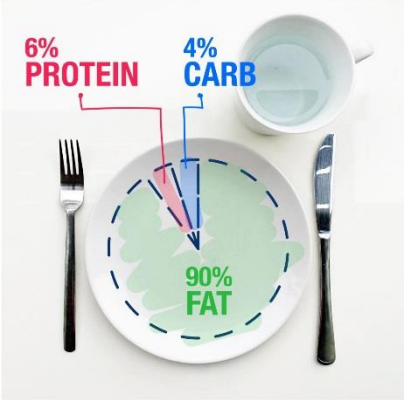
Modifed Atkins



LGIT



Classic



Pictures courtesy of Charlie Foundation

Mechanism of Action

- Likely to be multifactorial and still not fully understood
- Fasting and the KG diet result in change in plasma ketones, glucose, insulin, glucagon, and FFA levels.
- This occurs within hours. Anticonvulsant effect though delayed by a couple of weeks.

Efficacy of the classic ketogenic and the modified Atkins diets in refractory childhood epilepsy

Jeong A Kim, *Jung-Rim Yoon, †Eun Joo Lee, *Joon Soo Lee, *Jeong Tae Kim, *Heung Dong Kim, and *Hoon-Chul Kang

Epilepsia, 57(1):51–58, 2016
doi: 10.1111/epi.13256

Results/Efficacy

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- Study over 3 years (2011 – 2014)
- 1-18y
- Dietary naive
- Seizures >4 x/month
- Rx failure of more than 2 drugs

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- 104 patients – 51 KG diet, 53 MAD
- KG diet – 4:1 ratio
- MAD – CHO to 10g/day for 1st month, then may increase by 5g. Calorie restricted to 75%!

Table 3. The proportion of responders at 3 and 6 months of diet t

	Total			1 to <2		
	Classic KD (51) (%)	MAD (53) (%)	p-Value	Classic KD (17) (%)	MAD (20) (%)	p-Value
3 months after DT						
Seizure-free	17 (33)	13 (25)	0.374	9 (53)	4 (20)	0.047*
>90% reduction in seizures[a]	19 (37)	17 (32)	0.314	9 (53)	5 (25)	0.101
>50% reduction in seizures[b]	22 (43)	22 (42)	0.527	10 (59)	8 (40)	0.191
6 months after DT						
Seizure-free	16 (31)	12 (23)	0.461	9 (53)	5 (25)	0.101
>90% reduction in seizures[a]	19 (37)	16 (30)	0.474	10 (59)	7 (35)	0.194
>50% reduction in seizures[b]	20 (39)	19 (36)	0.321	10 (59)	9 (45)	0.515

DT, diet therapy; KD, ketogenic diet; MAD, modified Atkins diet.
[a]Includes children who reported seizure-free.
[b]Includes children who reported >90% seizure reduction and seizure-free.
*p-Value < 0.05, statistically significant.

Complications

- Exacerbation of gastro-oesophageal reflux
- Vomiting
- Constipation
- Diarrhoea
- Food refusal
- Renal stones (3-6%)

- Drowsiness (transient - at initiation)
- Increased bruising
- Pancreatitis
- Elevated serum lipids
- Osteopenia and an increased risk of fractures (long term)

Hypoglycaemia

Metabolic Acidosis

Hyperketosis

Ketogenic Dietary Therapy Service Team

Paediatric Neurologist –	Dr Paul Shillito &
	Dr Cameron Dickson
Ketogenic Dietitian –	Charlene Tan-Smith
Keto/ Epilepsy Nurse –	Dawn Anderson
Pharmacist –	Louise McDermott

Medication

How does it effect the Dietary Therapy?

Medications

- Patients are young/er
- Most will be on multiple medications
- Most of the medications = liquid form
  - Inability to swallow pills
  - Easier to administer (i.e. PEG or NGT)

Medications – ingredients with a carbohydrate value

- Brown/ Corn sugar
- Corn sweetener
- Corn syrup solids
- Dextrose
- Fructose
- Glucose
- High fructose corn syrup
- Honey
- Invert syrup
- Starch
- Lactose
- Levulose
- Maltodextrin
- Maltose
- Mannitol
- Manitolol
- Molasses
- Polycose
- Sorbitol
- Sucrose
- Xylose

Medication schedule	Am	Noon	PM	Total Carb (mg)
Clobazam (2ml x 2 per day) 1 ml = 2.5mg (1018mg/ml carbs)	5 mg (2ml = 2036mg carbs)		5 mg (2ml = 2036mg carbs)	2036 mg x 2 = 4072 mg carb
Sodium Valproate (600mg) 7.5ml x 2 twice a day (140mg/ml Carbs)	300 mg (7.5ml = 300mg)		300 mg (7.5ml = 300mg)	140mg x 15ml = 2100 mg carb
Lamotrigine (Lamictal brand brand) 1 tab (25mg) = ½ tab 2x/day (1tab = 26mg carb)	12.5 mg		12.5 mg	26 mg carb
Domperidone 4mg 3x/day (1 tab = 36mg carb)	4 mg	4 mg	4 mg	108 mg carb
Carnitine (Stevia) 6.8ml	500mg		500mg	0
Total				**6306 mg**

Medication schedule	Am	Noon	PM	Total Carb (mg)
Clobazam (10 mg tablet= ½ tab 2x/day) (109mg/tab carb)	5 mg (½ tab)		5 mg ½ tab	109 mg carb
Sodium Valproate (600mg) 100mg tab x1 twice a day 200mg tab x1 twice a day (100mg tab = 80mg carb/tab) (200mg tab = 18mg carb/tab)	300 mg (100mg x1 tab) (200mg x1 tab)		300 mg (100mg x1 tab) (200mg x1 tab)	196 mg carb (or 480mg –x6 100mg tab)
Lamotrigine (Lamictal brand brand) 1 tab (25mg) = ½ tab 2x/day (1tab = 26mg carb)	12.5 mg		12.5 mg	3 mg carb
Domperidone 4mg 3x/day (1 tab = 36mg carb)	4 mg	4 mg	4 mg	108 mg carb
Carnitine (Stevia) 6.8ml	500mg		500mg	0
Total				**416 – 700mg**

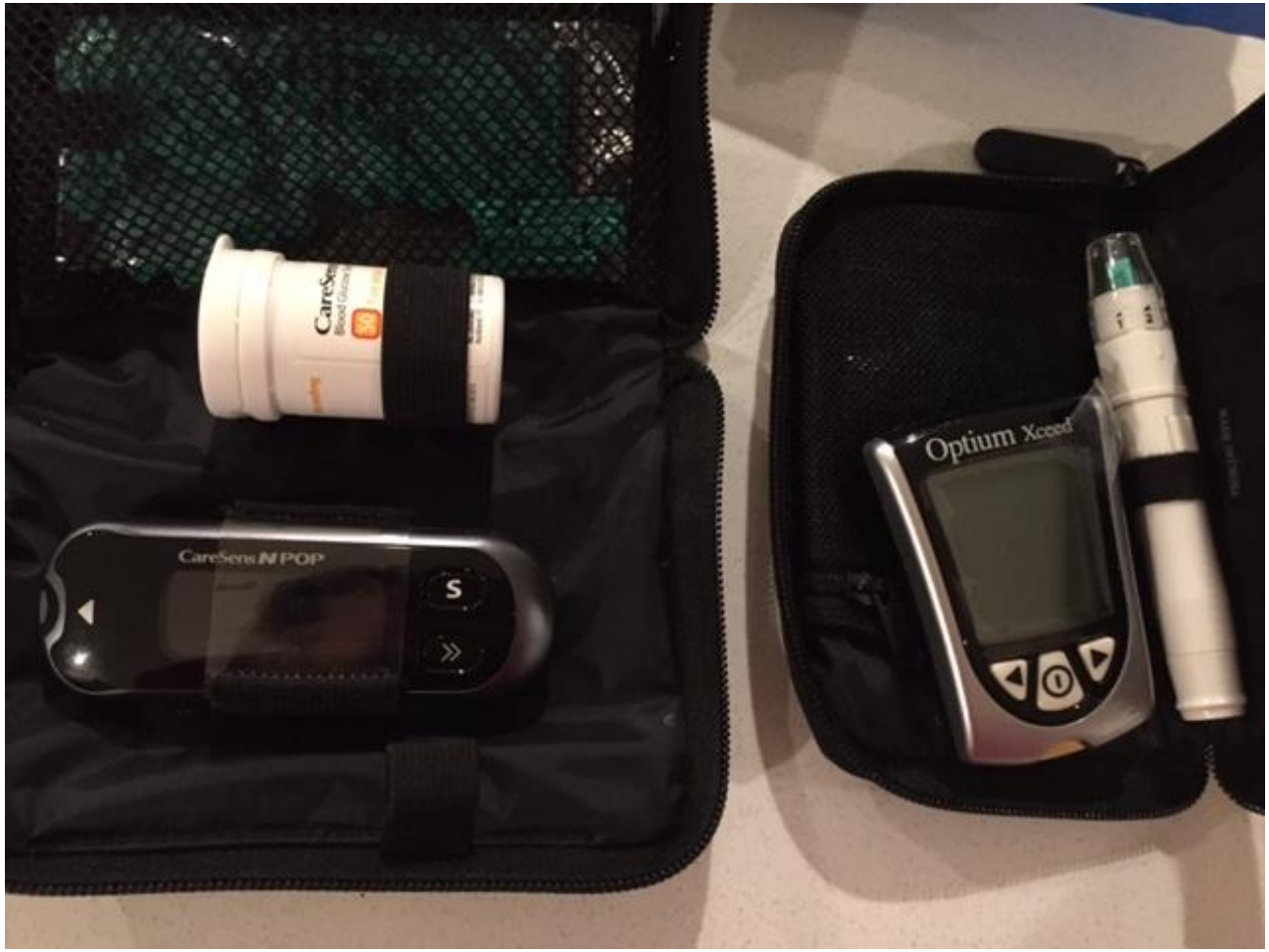
Medications

Drug	Liquid/ tablet	Carbs (mg)
Paracetamol (Paracare, API Healthcare)	Liquid 120 or 250mg/5ml	67.5% carbs e.g. 250mg = 168.8 mg carbs
Paracetamol 500mg DISPERSIBLE tab (Paragesic Soluble, Rex Medical)	250mg needed 1 tab dissolved in 10ml water = 5ml (250mg)	0 mg carbs in Tab
Ibuprofen (Fenpaed, AFT)	100mg/5ml **(Liquid)** (18.32mg carbs/ml)	e.g. 5 ml = 100g (91.6mg carbs)
Ibuprofen (Ibugesic, Rex Medical)	200mg/tab (69.84mg carbs/tab)	e.g. 100g (34.9mg carbs)
Ibuprofen (Nurofen, Reckitt Benckisser)	200mg/tab (116.1mg carbs/tab)	e.g. 100g (58mg carbs)

MEAL Prescription	Carbohydrate (grams)	Protein (grams)	Fat (grams)	MCT supplements (grams) 2g Liquigen = 1g MCT oil
BREAKFAST kcals 289 Ratio 4:1	3.5	4	18	24g Liquigen (12g fat)
			30g	
MORNING SNACK Kcal 148 Ratio 4:1	1.7	2	8	5g Liquigen (2.5g fat)
			15g	

DAILY TOTAL	Carb (grams)	Protein (grams)	Fat (grams)	MCT (grams)
kcal 1168 Ratio 4:1	13.9g % energy = 4.8%	16g % energy = 5.2%	79g % energy = 60.9%	41g % energy = 29.1%

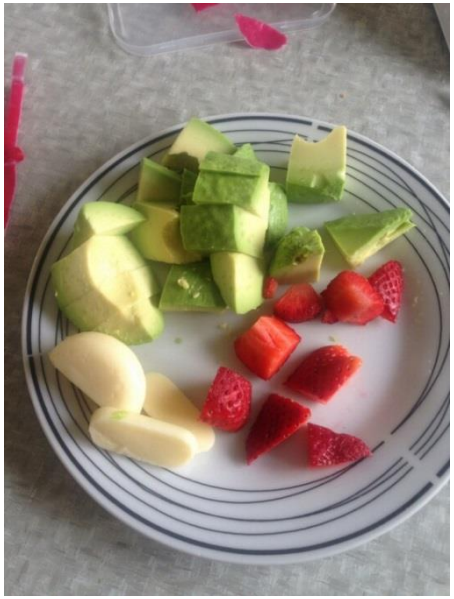
Blood sugar & Ketones tested x2 per day!



New Ketone & Glucose meter

Food Pictures

3 : 1 ratio
~ 87% fat



2 : 1 ratio
~ 80% fat

4 : 1 ratio
~ 90% fat

Case reports

Baby A
16 months old

Started
end Oct 2016

Modified Keto Diet

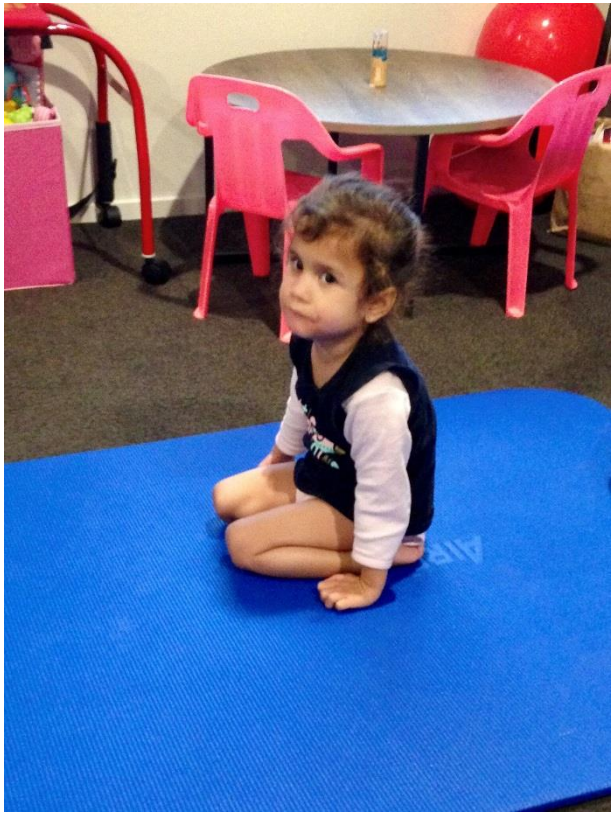
Oct 2016 Start ->
2 – 3 seizures per day

July 2017->
1 – 2 seizures per week

Feb 2018 Start ->
Started to weight
bear on walker

May 2018
Started to walk

May 2018 Start ->
Stand up
unassisted



May 2018
Sit up unassisted

J Boy
8 years old

Started
end Jan 2017

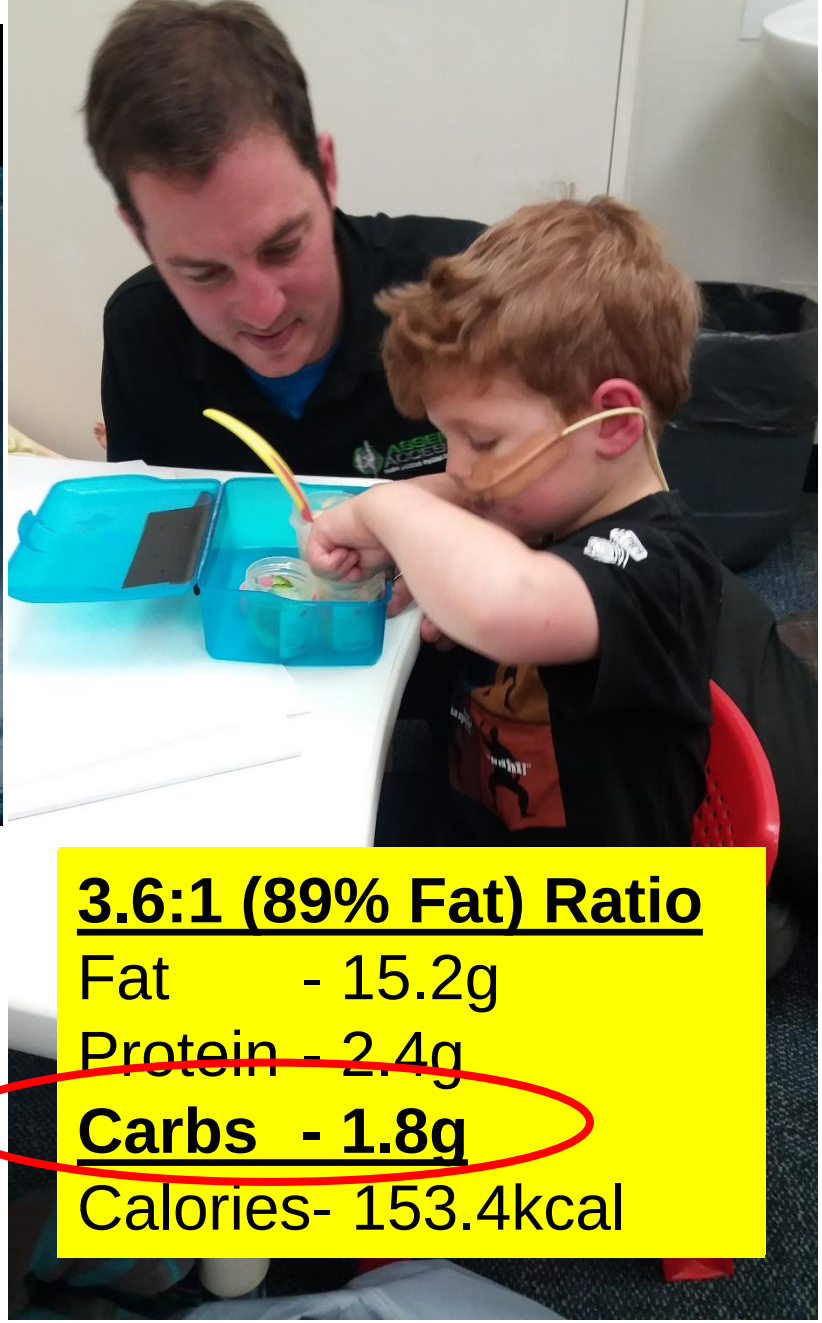
Modified Atkins Diet
(MAD)

Jackson’s video diary

Jake
3 years old

Started
end Aug 2016
(acute start)

Classic + MCT
April 2017=>LGIT



8g	Cheese Mild (Alpine)
15g	Clearwater Clotted cream
13.5g	Cucumber, Telegraph (NZ)
3.2g	Olive oil
16.2g	Strawberry, raw (NZ)

3.6:1 (89% Fat) Ratio

Fat - 15.2g

Protein - 2.4g

Carbs - 1.8g

Calories- 153.4kcal

Dec 2016
Seizure free

Jan 2017
rehab started

May 2018


15
16
17

Thank you

Ketogenic Dietary Therapy Service

For the Treatment of Children with Epilepsy

Canterbury District Health Board
Te Poari Hauora ō Waitaha

International Results

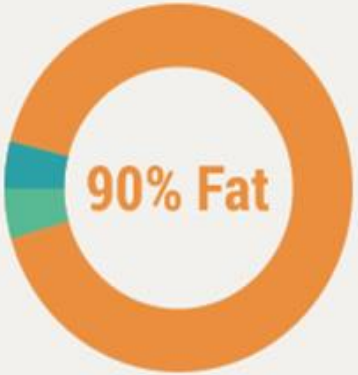
50% to 60% of patients seizure reduction 50%

30% of patients seizure reduction 90%

10% of patients no result

10% of patients seizure free

Classic Ketogenic Diet



4 : 1 Ratio

FAT : Protein + Carbohydrates

Approx. 90% Fat

10g Carbs per day

0.1g weighing of ingredients

Rethink the Pyramid

25% Drop Out
It's not easy to do

Eating so much fat can lead to constipation, nausea and vomiting

2 years
Wean and keep benefits

After two consistent years, the diet is slowly removed and the benefits have a high chance of remaining. Saving on a lifetime of hospital visits and medication costs.

1% 60/6000 births/yr have epilepsy

20-30% 12-15 not controlled by medicine

75% of patients consider the diet

10 funded patients per year

Discovered in Biblical Times

Ketosis Simulates Starvation Tricks the Brain

Not a Fad Weight Loss Diet

August 2016 We started

Neurologist Dietitian Nurse