



The Ketogenic Diet in Bristol

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Background

- Bristol is a centre for paediatric neurology but did not have the dietetic staffing to offer the ketogenic diet
- March 2003 KJL moves to Bristol as Head of Nutrition and Dietetic Services in North Bristol.
20% of time for clinical work.
- My predecessor was a Renal Dietitian – not my area!



Background (2)

- My background was in paediatrics.
- Opportunity to use my one a day a week for a new service to paed.
- Knew that there was a need for ketogenic diet service and had a small amount of previous experience with it.



Background (3)

- The paed neurologists in Bristol work across both acute Trusts
- North Bristol NHS Trust (where Neurosurgery is provided and I work) and
United Bristol Healthcare Trust (– in which the Children’s Hospital sits.)
- Epilepsy Nurse Specialist works across both. We had previously worked together elsewhere.
- Approached Paed Neurologists about possibility of starting a service for ketogenic diets –welcomed with open arms!



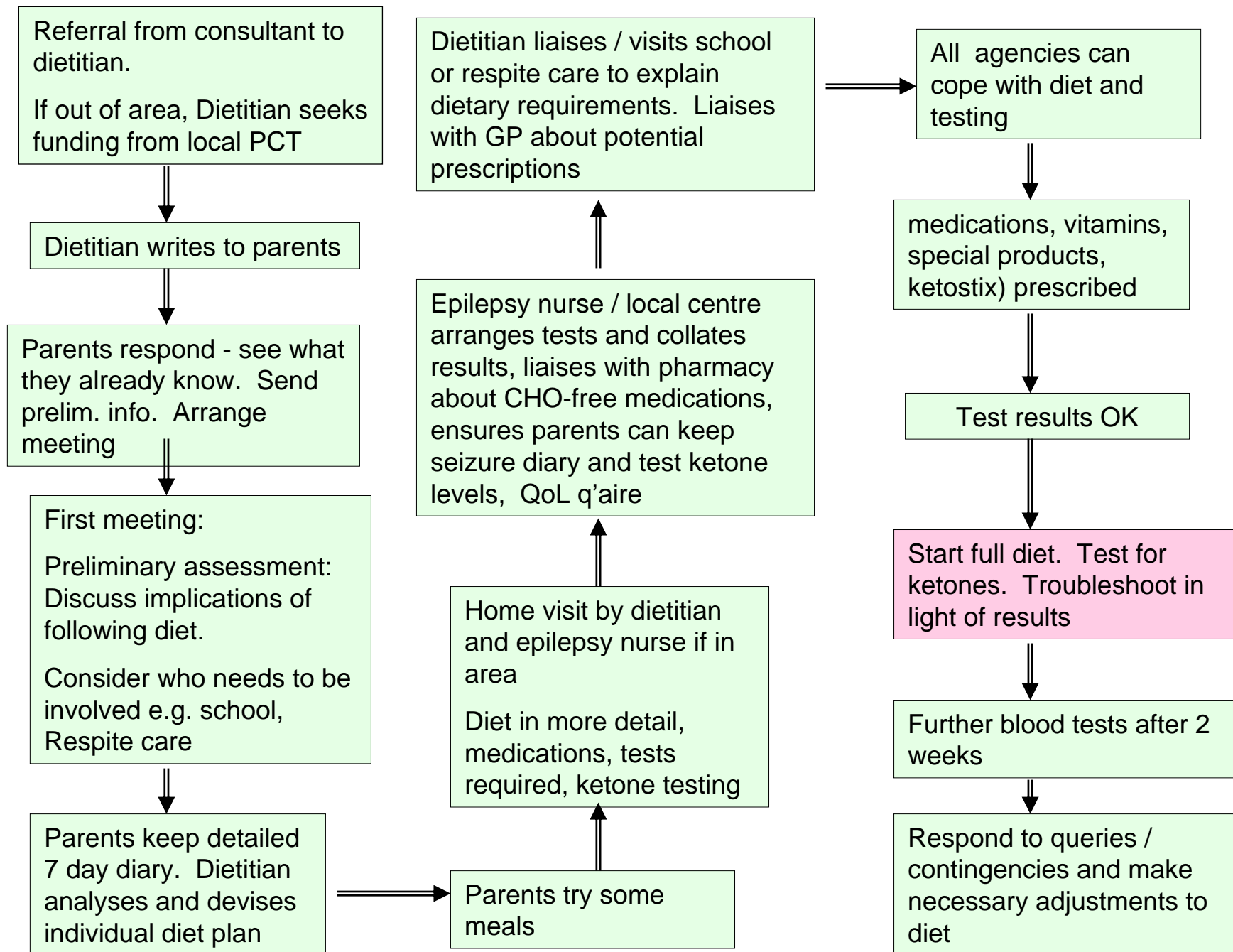
First patient

- K aged 9
- Intractible polymorphic epilepsy
- Eats what's put in front of him but doesn't raid the fridge or take other people's food
- Already well-known to Epilepsy Nurse Specialist
- Also came with fabulous family!



Which Diet?

- Classical
 - MCT
 - Modified MCT
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- I use the Classical as a first line then use MCT as a 'fallback' if I can't get high enough ketone levels or if a more relaxed diet would be helpful.





What starting point?

- Start with a 3:1 ratio but expecting to go to 4:1.
- Based on my assessment of usual Calorie intake
- Meal pattern in line with usual meal and snack pattern (but add bedtime snack if that isn't usual)
- Pre-diet preparation includes trying recipes and meals so we can be sure the child will eat the food.



My counting system

- Fat units: 10g fat each
 - Protein units: 6g protein each
 - CHO units: 5 g CHO each
 - Free Foods: don't need to be counted
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- I give a lower CHO allowance in order not to have to count the CHO in the free foods.
 - Also prefer to count the protein entirely from 'proper' protein foods rather than bits in cream, veg etc.



Fat Units (10g)

- 12 g butter
- 25g mascarpone cheese
- 42 g double cream
- 25g crème fraiche
- 13g mayonnaise
- 50g avocado flesh
- 13g macadamia nuts
- 10g oil



Protein units (6g)

- 25g lean cooked bacon
- 20g cooked lean beef or chicken meat
- 22g cooked lean pork or lamb meat
- 26g prawns
- 26g canned drained salmon
- 30 g cooked white fish
- 50g egg
- 24g Cheddar



Carb units (5g)

- 45g apple flesh
- 20g banana
- 50g beetroot
- 85g blackcurrants
- 100g carrots
- 45g kiwi
- 110g raspberries
- 85g strawberries
- 160g tinned tomatoes
- 70g watermelon flesh



Count all Carbs or have free foods?

- Depends on what child usually eats
(e.g. if eats no veg – no point)
- Depends on family's preferences
 - And if likely to use EKM



Free Vegetables

**aubergine,
asparagus
broccoli,
Brussels sprouts,
cabbage,
cauliflower,
celery
chicory,
cress,
courgettes,
cucumber,
curly kale
endive,**

**green beans (French
and runner)
leeks
lettuce,
marrow,
mushrooms
mustard and cress,
okra
olives,
spinach,
spring greens,
Swiss chard,
Watercress
zucchini**



Other Free Foods

- Sugar-free drinks (check the carbohydrate content is virtually zero)
- Black tea, black coffee
- Gooseberries
- Vinegar
- Sugar-free jelly e.g. Bird's or Hartley's
- Saccharin, Liquid sweetener (Hermesetas),
- iced-lollies made from diluted diet squash
- 1 teaspoon cocoa powder (*Not* drinking chocolate)
- Salt, pepper, herbs, spices, Bovril, Marmite, stock cubes, Oxo
- Food essences, food colourings



Free veg needing more care

- bean sprouts
- carrots
- fennel boiled
- Lemons
- pumpkin
- Rhubarb
- tomatoes – raw

cabbage white
cucumber
gherkins
peppers – green and red
radish,
swede
turnip



Example

- 9 year old boy
- weight 30kg
- usual energy intake about 1450 Cals

3:1 Ketogenic diet prescription

- 140g fat (14 fat units)
- 30 g protein (5 protein units)
- 15 g CHO (used for free foods)

Ketogenic Diet units - a rough guide				
weight g	Food	Protein units	Fat units	CHO units
50	avocado pear flesh	0	1	0
12	Butter	0	1	0
25	Crème fraiche (full fat)	0	1	0
20	Double cream	0	1	0
10	Lard	0	1	0
25	Mascarpone cheese (full fat)	0	1	0
13	mayonnaise (retail)	0	1	0
10	Olive oil	0	1	0
25	Olives in brine, drained	0	0.5	0
25	Philadelphia	0	1	0
10	Rapeseed oil (veg oil)	0	1	0
	All meats and fish are cooked weight			raw weight
25	bacon lean only	1	0	0 30
25	beef, lean only	1	0	0 30
25	chicken, lean only	1	0	0 30
25	corned beef	1	0	0 N/A
25	Duck (no skin)	1	0	0 30
25	Ham , lean only	1	0	0 35
25	lamb , lean only	1	0	0 30
35	mackerel (smoked)	1	1	0 35
25	pork, lean only	1	0	0 30
30	salmon, canned in brine, drained	1	0	0 N/A
30	salmon, steamed	1	0	0 35
30	sardines in oil, drained	1	0	0 N/A
75	tofu	1	0	0 N/A
25	tuna in brine, drained	1	0	0 N/A
30	white fish, cooked	1	0	0 35
25	prawns, boiled	1	0	0
	Eggs and Dairy			
50	eggs	1	0.5	0
25	Cheddar / stilton	1	1	0
105	semi-skimmed milk	0.5	0	1
65	natural low fat yoghurt	0.5	0	1
55	natural Greek yogurt	0.5	0.5	0.5
	Nuts			
18	almonds	0.5	1	0
15	brazil nuts	0.5	1	0
60	tinned coconut milk e.g. Barts	0	1	0
16	Coconut - dessicated or creamed bloc	0	1	0
16	hazel nuts	0.5	1	0
13	macadamia nuts	0	1	0

Tuna and mayonnaise and Double cream jelly



Ketogenic cauliflower cheese (and ?swede)





...then along came EKM

- Some parents prefer using EKM to have more freedom of choice
- Allowance allocated for each meal
- Example:
 - 59 Fat, 9 Protein, 7 Carb = 3.7:1 ratio

Ketone Testing

Either urine or blood testing

Urine ketones

Aim: 8 – 16 morning
and evening



Blood ketones

Aim: 4 mmol/l





Trouble shooting if ketones not high enough

Dietary causes

- People being 'helpful'
 - Foods not being weighed
 - new drug which isn't sugar free
 - Anything else being taken?
-
- if still can't get ketones to required level
add Liquigen (MCT) and MCT oil



Our experience in North Bristol

04/06

To date:

- 30 children have been referred
- 4 were too far out of area - of which 1 was taken on by the local dietitian
- 1 advised by neurologist to try Atkins (teenager)
- 2 negotiating with local PCTs for funding
- Leaves 23



Our experience in North Bristol

04/06

To date:

23 'eligible' referrals

- 23 children contacted by me
- 5 decided not to go ahead once they knew more about the diet
- 1 has never made contact with me
- 1 may not benefit from diet so being considered further
- Leaves 16

Outcomes

16 started diet programme

- 1 started diet but would not do the pre-diet work and diet failed
- 6 showed no benefit after three months (or longer)
- 6 remain on diet after 3 month trial
- 1 still in 3 month trial period – but showing benefit
- 2 in pre-diet preparatory phase



Child A – typical outcome

- Intractable epilepsy, multi seizure types
- May+ June seizures most nights and every 3rd day
- Commenced diet July 2004
- Now: No seizures in day, 2 at night every few days. Seizures shorter in length. Hospital admissions now overnight rather than days.
- 'Brighter in himself'



What's changed since we started?

- Start with 3:1 diet but explain likelihood of needing 4:1 depending on ketone levels
- Consider MCT earlier
- Food composition tables!
- EKM
- Dietitian takes responsibility for seeking funding if needed



Unclear areas

- What are the ideal ketone levels for this particularly child?
- Could we start with an Atkins type diet?
- Is it impossible to get high ketone levels in some (older) children?
- Do we need 2 years on diet before relaxing diet? After a year on the diet, could the child be just as well on lower ketone levels?
- Do we need so many pre-diet tests?



Pre-diet tests

- Renal U/S
- EEG
- ECG and / or Echo
- acyl carnitine profile
- U+Es
- Liver function tests (LFTs)
- Fasting Lipids
- Glucose
- trace elements and vitamins
- RBC and WBC
- urinalysis
- Weight, height and HC



Problem areas (Bristol)

- **If child has to be admitted to hospital**

Dietetic staff at Bristol Children's do not get involved in ketogenic diet so no-one to liaise with all parties involved

- **Liaising and getting test results**

- Actions if results are abnormal

- **Monitoring children who come to clinic elsewhere**



Problem areas

- **EKM**
 - Assumption that the computer is 'right' – being very precise about ratios
 - Who knows if food composition is the same as the food tables?
 - And how accurate is weighing?
 - Also differences in what's absorbed by the intestines

- **Matthew's Friends**

Parents talk to each other!



Parents and teachers comments

- It's not so much food and eating as trying to provoke a chemical reaction in the body
- Yes – the diet is a hassle – but the effect of my child's fitting on the rest of the family is more hassle.
- Happy and vocal, much nicer to have in class (was previously unhappy and 'grizzled')
- Much brighter, not sleeping in afternoon, conversation and mobility better
- No seizures since started the diet!