Thank you to Dr Moudiotis for his slides and mum for her insights and memories

NHS
Royal Devon
University Healthcare
NHS Foundation Trust

Managing an infant with T1D

A dietitians view

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Diagnosis

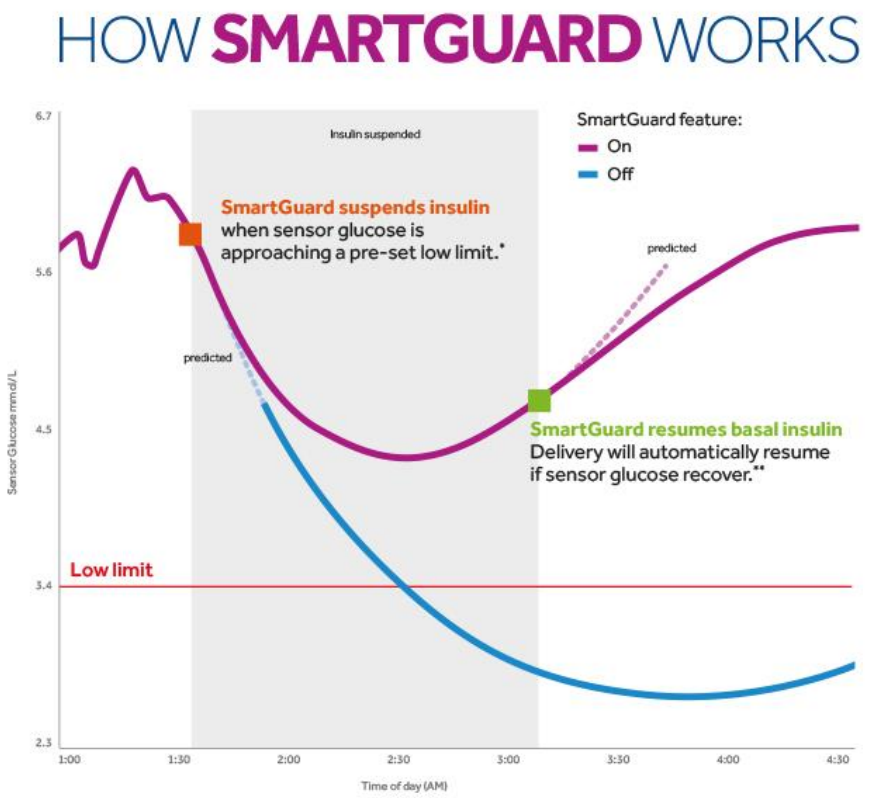
- **Elective Caesarean 39 weeks**
- **BW 2960g**
- **Normal pregnancy, no risk factors for sepsis, regained birth weight by Day 4 breast feeding**
- **15 days old**
- **24 hour history of lethargy, poor feeding, vomiting and weight loss**
- **O/A jaundiced, sunken fontanelle, grunting, peripherally shut down**
- **Serum glucose 37.5mmol/L, pH 6.91, bicarbonate 1.9mmol/L, blood ketone 4.7mmol/L**
- **Hb1Ac 83 mmol/mol**

Initial treatment

- DKA – resuscitated and transferred to Tertiary PICU
- Remained in-patient for 3 weeks; then discharged back to RDE
- No cerebral oedema
- Came to us 640G Medtronic pump with Guardian 3 sensor
- Predictive Low Glucose Suspend and micro-bolusing with breast feeds
- Transfer back – symptomatic hypoglycaemia in a service station on the M5

Tackling Glucose Variability

- Breast feeding important to continue but managing glucose levels in hospital tricky
- Micro-bolusing for breast feeds and PLGS actually led to wide fluctuations in BG levels with rapid falls requiring multiple Glucogel admin
- Some success with fairly flat basal profile and Suspend on Low set at 5 mmol/L mark with micro correction boluses every 3 hours using sliding scale
- Team approach



Type of Diabetes

- No sign of exocrine pancreatic insufficiency (normal stool, weight gain, normal faecal elastase); normal pancreas visualised on USS
- Negative autoantibodies (GAD, IA2, ZnT8)
- C-peptide: 47pmol/L – this fell to < 3pmol/L one month after diagnosis
- T1D – Genetic Risk Score: 52%
- Targeted Next Generation Sequencing – no mutation identified. Not suitable for sulphonylurea

DiabetesGenes

https://www.diabetesgenes.org/

EXE TID

Understanding beta-cell destruction through the study of EXtremely Early-onset Type 1 diabetes
(A Musketeers' Memorandum Study)

Breastfeeding

Infant feeding patterns are unpredictable, breastfeeding can be associated with a variable duration and volume of feeding, and carbohydrate counting is difficult, all of which can increase the risk of hypoglycaemia

Rabbone *et al* (2017)

*Mature breast milk
(8-12 feeds)

7.2g carb/100ml
69kcal/100ml

*McCance & Widdowson COFID online

EAR 1-2 months 526kcal/day

so estimated 526kcal Breast Milk
~760ml/55g carb per day
~5-6g per feed (range 4.6-6.9g per feed)

GOSH 5th Edn Sept 2014:

Rabbone et al (2017) Insulin therapy in neonatal diabetes mellitus: a review of the literature Diabetes Research and Clinical Practice 129 p126-135

Dosing for breastfeeding

Aim to achieve optimal blood glucose control of 6-12mmol (higher target range due to age).

No bolus dose of insulin with feeds

Administer Insulin (Novorapid) via a pump as a correction dose every 3 hours as required.
Ensure 3 hour gap between Novorapid doses.

Blood glucose (mmol)	Insulin dose (units)
12-16	0.1
16-20	0.2
20-24	0.3
>24	0.4

Resolve any hypoglycaemic episode prior to giving breastfeed

Care plan

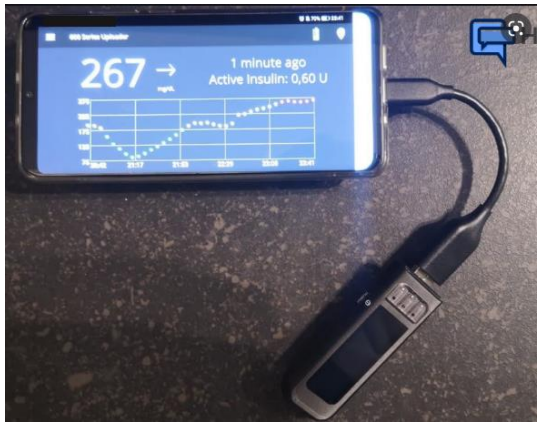
- **A 2008 review (Pinelli *et al*) provided usage recommendations for insulin pump therapy in Italy revealed a large variation in the total daily insulin dose used in CSII for Neonatal Diabetes Mellitus (0.2–1.4 U/kg/day, with the basal rate accounting for 20–50% of this).**
- **Pre-meal boluses ranged from 0.05 to 0.2 U/meal or 0.01–0.1 U per 10–15 g of carbohydrate. An insulin corrective factor of 0.1 U for every 100 mg (5.6mmol) above 150 mg/dL (8.3mmol) of glycaemia, and a reduced night-time basal rate, were also suggested.**

Findings were based on data from five publications involving a total of up to 21 neonates.

Cited by Rabbone et al (2017) Insulin therapy in neonatal diabetes mellitus: a review of the literature Diabetes Research and Clinical Practice 129 p126-135

4 months old

- Average BG 13; HbA1c 78mmol/mol
- No severe hypos.
- Why? infant physiology, erratic feeding, NR not fast enough, no endogenous insulin
- Parental burden ++, no sleep 1.5hr shifts; can't work
- 640G + Guardian sensor
- Contour Link glucometer – OTG cable – Android phone – Nightscout – CGM on phones and iPads in bedroom & kitchen
- Management: Nightscout day-to-day ; Carelink trend analysis



5 months

HbAc1 88mmol/mol

Hard times: ‘bad weeks’ means you don’t leave home

‘Looking after him is a 2 person job, seeking reassurance from each other and having to make at least one complex decision a day regarding his glycaemic care’

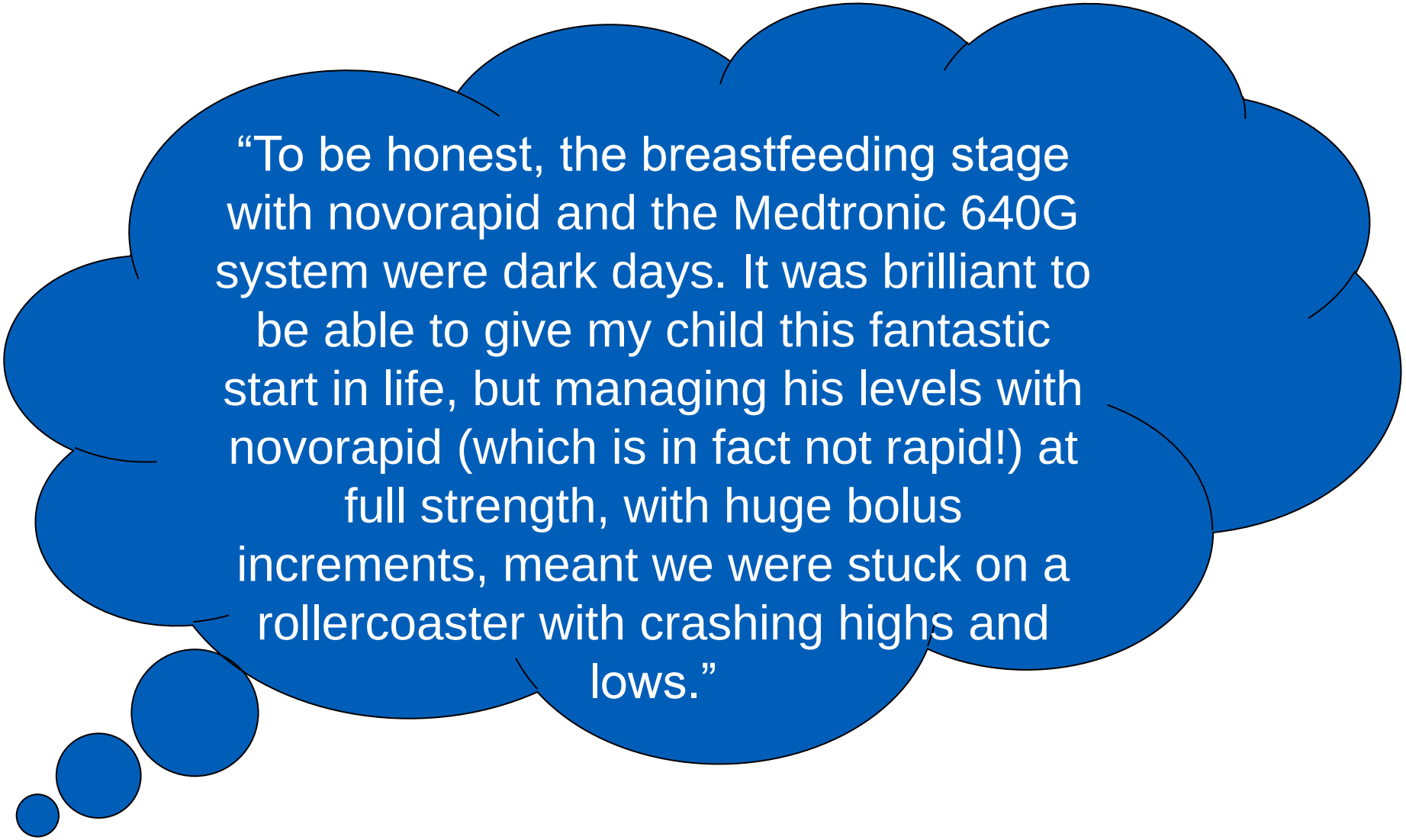
Setting hourly alarms overnight to ensure his BG levels are OK

Basal rate 73% TDD – switch between 2 different rates

Suggestions:

No longer feeds overnight – opportunity to find the ‘correct’ basal rate overnight

Introduce solids – tasters only fruit/veg


“To be honest, the breastfeeding stage with novorapid and the Medtronic 640G system were dark days. It was brilliant to be able to give my child this fantastic start in life, but managing his levels with novorapid (which is in fact not rapid!) at full strength, with huge bolus increments, meant we were stuck on a rollercoaster with crashing highs and lows.”

8 months

- No developmental concerns
- Body needs more insulin? Episodes of ketosis not attributable to cannula fail
- Introducing complex carbs into diet – 1 unit : 40g carbohydrate (TDD divided by 300)
- Variable eating of an infant #QuicheGate

12 months

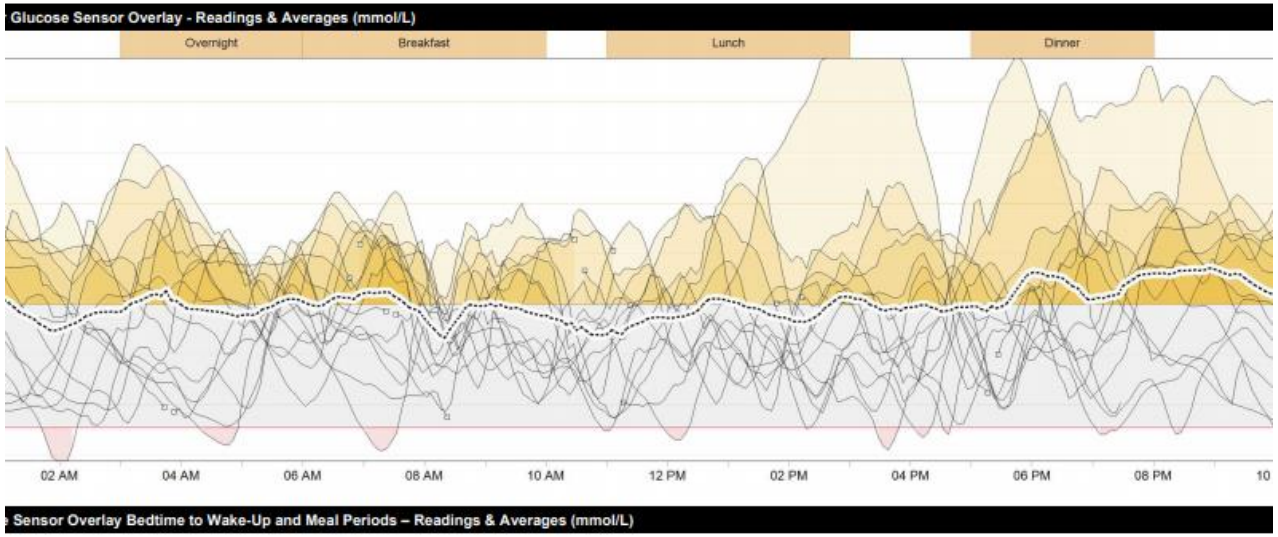
- HbAc1 73; average BG at clinic 10.4mmol/L
- 12m Schedule of Growing Skills – normal
- Still trying to move to a bolus basal regimen based on CHO counting and ratios

On to the food stage… the most valuable advice we had was that the order of food matters. Meaning that wherever practical, we give our child protein or vegetables before we let loose on the carbs.

More generally we try and ensure that meals are balanced with longer acting carbs, healthy fats and proteins. Without the fats and proteins we have always struggled with the nasty tail of insulin (especially novorapid at the 4-6 hour mark) - and would rather try to prolong digestion time than mop up residual meal insulin with a sugary hypo treatment.

14 months

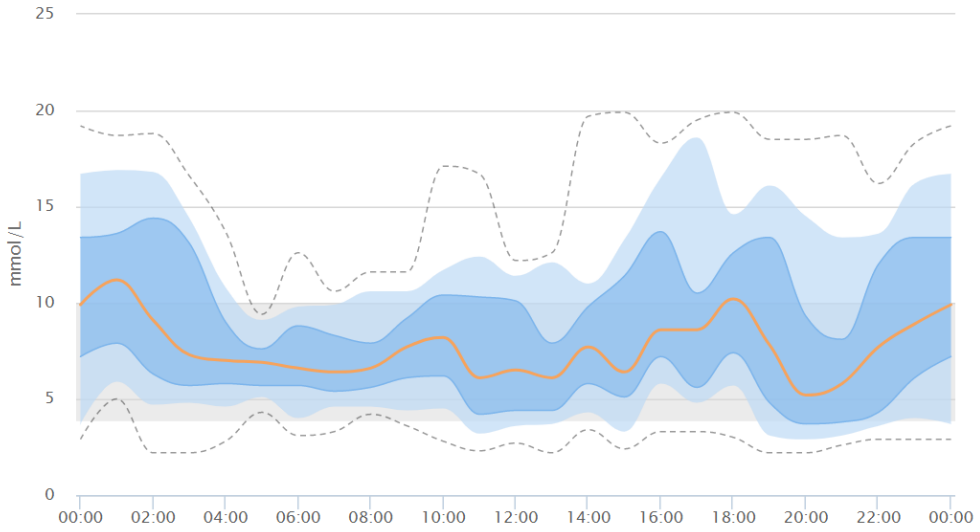
- Managed to reduce HbAc1 from 83 to 70mmol/mol but no further
- Parents frustrated by lack of progress and fear dysglycaemia on developing brain
- Hypoglycaemia: PLGS doesn't ameliorate hypos; last month they were using multiple daily doses of Glucogel; changing basal rates overnight led to BG levels being too high or too low
- Medics always trying to increase TDD of insulin
- Agreed ratios 1unit:35g, ISF 22, TR 5-10 and AIT 4 hours



Now he is 3 ¾

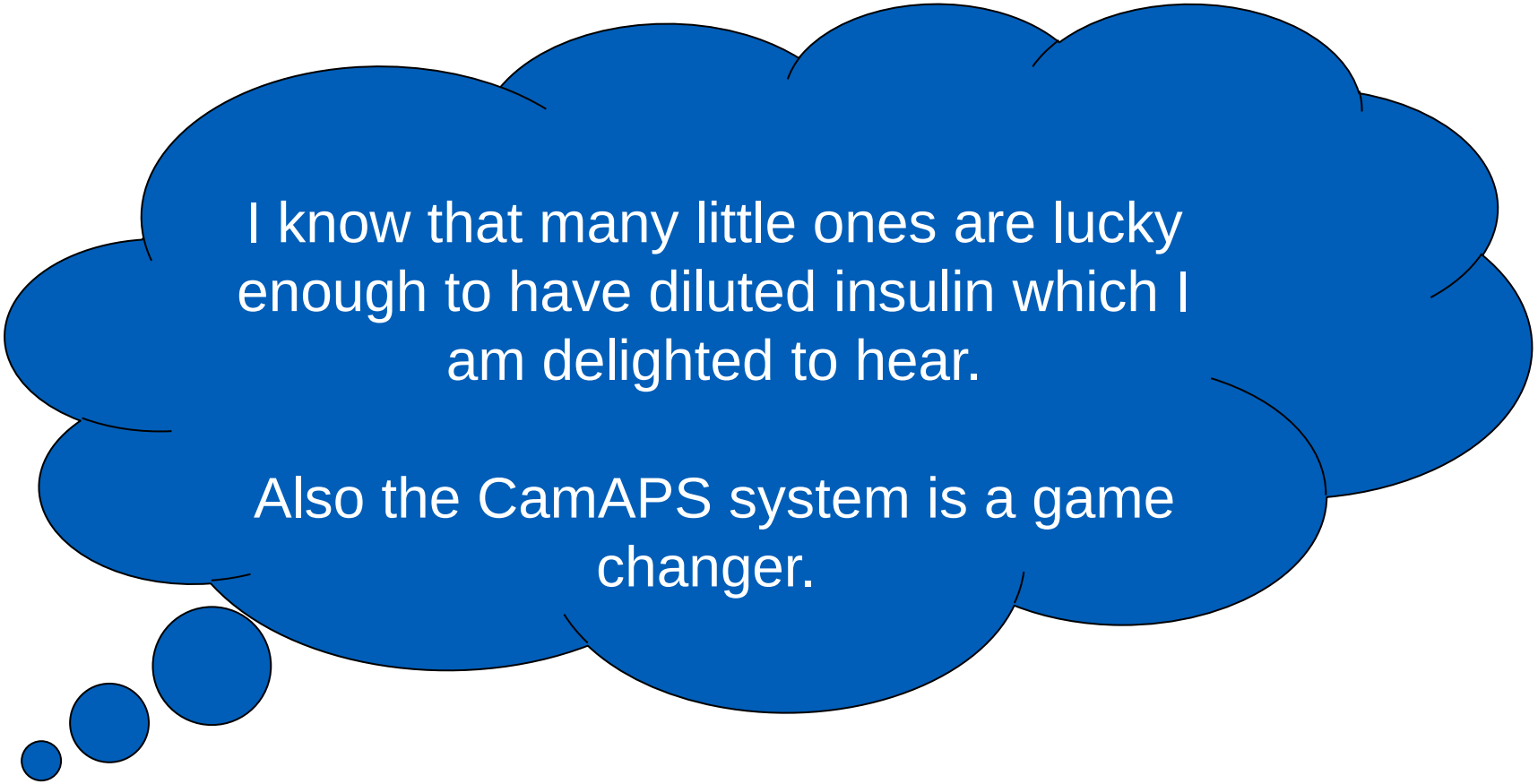
- Age 18 months – parents started a DIY open loop
- Age 23 months – CAMaps
- Age 3 ¾ Ave BG 8.3mmol, ↓TDD 5.5 units & SD 3.3units

Coefficient of variation (CV): **46 %**
Glucose management indicator (GMI): **51.7 mmol/mol - 6.9 %**

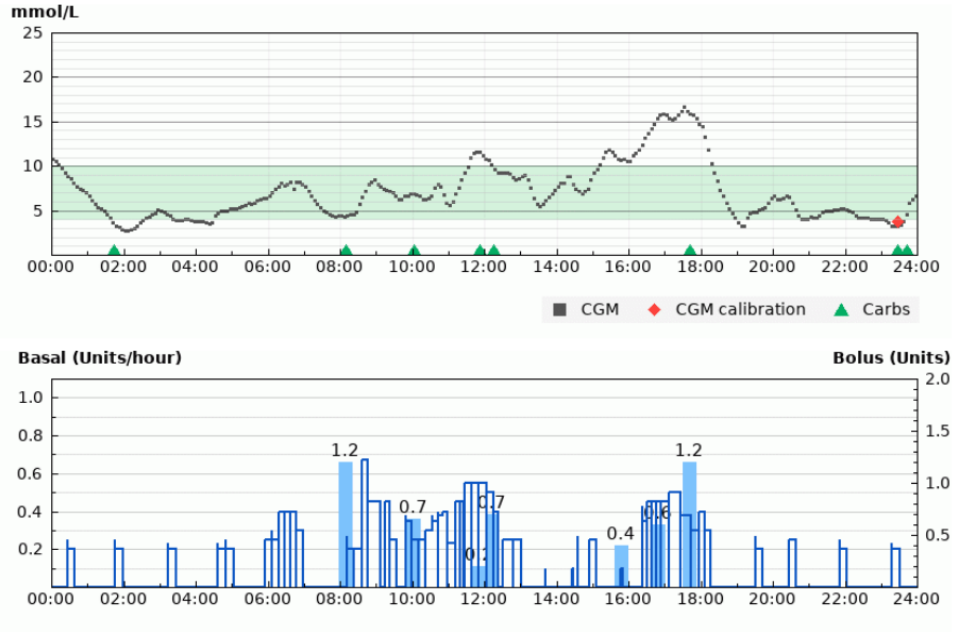


Show active basal profile

Very low	Low	Time in Range	High	Very high	Time CGM active
< 3.0 mmol/L	3.0 - 3.9 mmol/L	3.9 - 10.0 mmol/L	10.0 - 13.9 mmol/L	> 13.9 mmol/L	
3 %	**7 %**	**63 %**	**18 %**	**10 %**	**64 %**


I know that many little ones are lucky enough to have diluted insulin which I am delighted to hear.
Also the CamAPS system is a game changer.

What have we learnt? Diluting insulin?



Benefits those with low insulin requirements – unable to dose the basal effectively

- **Diluting medium available: 0.3ml insulin with 2.7ml diluent to give U10 insulin**
- **Pharmacy prepared or done at home?**
- **Need to change steel cannula every 48hrs**
- **Rates have to be 10x stronger i.e. ratios 1 u: 3.4g not 34g**
- **Need safety labels, alert on our EPR & written plans for pump failure**

CDEP Diluting insulin YouTube

Overall, whilst not 100% food related, the insulin used has a massive effect on everything. Luckily we now have faster acting fiasp insulin as opposed to novorapid. It means we can be more relaxed about what and how much our child eats and just top up insulin levels knowing the blood sugar levels won't peak too badly. This is important for everyone's long term mental health as it reduces anxiety around food and meals. In young children it reduces the power they can exert over adults, such as refusing to eat or holding out for something better etc.

Mums advice

Tricky issues:

- Developing a sweet tooth - for us this is more pronounced in a child that has been exposed to refined sugar from a young age. We *try* to avoid refined sugar.

- Having to “feed the insulin”, especially a meal bolus tail, leading to poor food choices and a lack of clear routine. This has plagued us for years, but the insulin change itself has made a big difference.

- Teeth (according to the dentist) drink water after any sugar and use mouthwash as soon as they’re old enough to.

- The child saying no. This is a massive issue with toddlers, so most healthy ideas are completely disregarded in the name of safety. To ensure they do take any necessary hypo carbs, virtually any form that will avoid a tantrum or refusal will do!

Mums advice

General tips for young children:

- Night time hypo treatments: a calpol syringe of honey. Less spiky than glucogel.
- Learn quickly which foods are high carb foods v low/no carb foods.
- Learn about GI and how to make a meal slower to absorb, eg cooling and re-heating pasta, adding (healthy) fat to high carb meals eg nut butters.
- Going to sleep with a tummy full of protein/fat rich foods will cause a night spike. Whilst the UK only gives insulin for carbs, paying attention to the FPU at night is necessary.

Thank you

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