Fighting Fits with Fat

A parent's perspective by Lynne Goodwyn

"Have you ever heard of the Ketogenic Diet?"

This was the question I was asked one morning at school drop off. I was looking particularly haggard, having had little sleep or rest for, well, years actually.

We had lived with intractable epilepsy for six years; seizures most nights, sometimes in the early hours or at school, but usually associated with sleep. Holly wasn't supposed to have epilepsy. Having suffered birth asphyxia, she had a diagnosis of Athetoid Cerebral Palsy, but, we were reassured, without any of the common additional complications. The first seizure struck at 20 months. From there life spiralled down a very dark tunnel. Our bright, sprightly, determined little girl literally wasted away before our eyes.

I was well aware that other children had much more frequent seizures, but Holly's were changeable and severe. At the end of every fit, just when her little body started to relax, so did her breathing, often to a complete stop. Sachets of diazepam could be found in every handbag, coat pocket and glove box in our cars. Our house was wired with CCTV so we could watch Holly fall asleep and catch a seizure early, and on several occasions get her to A&E before further brain damage occurred. We were never without our mobile phones. Our whole lives, including those of our other children, revolved around Holly and her epilepsy. Even her own therapy, so important in those early years, took a back seat. We were exhausted, but nevertheless accepting that this was how life was to be.

My answer to the question was, "I have, but our paediatrician thinks it would be cruel to take away chips and chocolate when Holly has so little else in her life. Besides, it probably wouldn't work with her". My friend smiled sympathetically and arranged for me to meet someone who would change my mind.

It took for Holly, age nine, to be ventilated in ITU, painfully skinny with thin hair and pale skin, lacking enough energy to rebound between seizures, for her doctors to agree that something drastic needed to change if this tiny girl was to survive childhood. It wasn't that they didn't care; far from it, but the Ketogenic diet was not popular and had little research base.

The team at GOSH were particularly interested that Holly had fewer seizures when she was unwell. To the team, this meant she responded well to ketones. They made the diet sound easy, just following a recipe, albeit a strange one. I had a child that ate carbohydrate almost exclusively, but she was willing to try these new things and understood the implications. We started the diet on March 14th 2006 and within days Holly looked different. Her eyes were more open, alert. The report back from school was the same - Holly was waking up. She started to get vocal, shout out in class. "I love Liam" was her favourite.

After twelve weeks seizure free Holly had a full tonic clonic and we thought that was it, our time on the diet a nice break, shortly lived, but Holly went another ten weeks without any seizure activity, then bigger gaps. As per the trial, we had to wait six months before starting the medication wean. We were told this would be when we would have the most noticeable improvements. In all it took another 18 months to wean Holly off all the medication, but the result was fantastic. This approach was an absolute success for Holly, so much so that she stayed on the diet long after the trial had finished. She tolerated the meals, made up her own recipes and adapted it to her tastes and activities. We learned how to be flexible within its rigidity.

Our top tips for the diet would be:

1. **Bulk produce where possible. We made ten main meals at a time and froze them for speed during the week. Holly could still join in with family meals, such as Sunday roast, but she always had options.**

2. **Have salads as back up. If we were eating out we always took a cold meal. Early on in our Ketogenic time we went to a well-known heritage site and asked for them to warm up Holly's meal. After much explanation and objection on their part they agreed, only if we signed a disclaimer to say we were responsible for the heat of the food. It's the only place where the words "medical diet" and "GOSH" have had no effect!**

3. **You can never have too many pots. We now have shelf-loads of redundant plastic pots of various sizes. We also could not have lived without mini spatulas to get that vital last drop of butter.**

4. **Communication! Talk to everyone about the diet, anyone who comes into contact with your child - family, friends, carers and school. I booked a slot on the staff training days at the beginning of each year (more frequently if staff changed), so that anyone with the potential to put food in Holly's mouth knew exactly what could and couldn't go in. I told everyone this is a "drug-free approach for epilepsy" not just a diet. Even after seven years, mistakes were made; new assistants at school or just complacency. I have been known to take photos of pots and weigh out left butter then present it as a percentage of fat intake for the day. Also talk to your child, learn what they like and don't like, if they are hungry the diet may need altering.**

5. **Don't try too hard. Holly was happy to choose her own meal and not necessarily match it to ours. Not only did this actually help her to gain some independence, it meant she didn't long for foods her siblings were eating. We decided it was unfair to restrict their intake of chocolate or fish fingers because their sister had epilepsy. Their lives were restricted anyway.**

6. **Special occasions can still be special. We made up a chocolate recipe on EKM. Holly was so excited, but the first time she tried it I had forgotten to add sweetener. We learned never to do that again!**

Without the Ketogenic diet our girl would have been lost in a swamp of seizures and drugs; most likely, she would have drowned in it. Now we have a vibrant, party-animal teenager who has achieved some GCSEs, goes out with friends, to parties (she organised her school prom) and plays Boccia and disability athletics at national level. The fear of epilepsy, returning to the life Holly had before the diet, never goes away, but she wanted to come off the diet and that wish had to be respected.

So far, she has been as fantastic off the diet as on it and continues to thrive in a way we never thought possible. Holly's ambition is to play Boccia for England and to own a knitting shop. The remarkable thing about that is that she has ambition. She is doing and achieving everything she wants to despite her disability and, I truly believe, because of the Ketogenic diet.

A message from Holly:

The diet was difficult at first - I was sick when the food was too much and I didn't like cream. But I felt better so it was OK. I knew it was making me better. I could do things, like sport, that I couldn't do before.

I know what I can have and I get cross if people get it wrong. They don't always listen to me when I say I have to eat all the butter, or if I need a snack. I used to worry if I hadn't had my lunch at the right time. I knew my recipes and what I liked. My sister liked my fish fingers, so they needed guarding - I couldn't share my food. I enjoyed cooking and I'm doing food science now – I like to cook for other people.

I really love chocolate!! Eventually I wanted to eat the same as my friends, to order from a pub menu. Now I can do that.