

THE HIGHS AND LOWS OF EPILEPSY AND KETOGENIC DIET THERAPY.

'Its monumental, its huge...the impact that the diet has made on his life in a positive - don't get me wrong, it's really hard, our life is not like most peoples' (FP19).

Family Experiences of Childhood Epilepsy and Ketogenic Diet Therapy: A Qualitative Study

Carroll JH¹, Parkin T¹, Hickson M¹, Cross JH², Williams E³, Aldridge V³, Collinson A¹

BACKGROUND

A diagnosis of drug resistant epilepsy is life changing for a family. Ketogenic diet (KD) therapy offers hope when other treatments have failed. However, it requires significant change in daily routine and dietary habits.

Aim: To explore families experiences of epilepsy and KD therapy

METHOD

- Interpretive description design.
- **Semi-structured interviews with 21** parents (UK and international) of a child aged ≤ 18 years with epilepsy, currently or recently treated with KD therapy.
- Interviews were audio recorded, transcribed verbatim, anonymised, coded using Nvivo (V12) and inductive thematic analysis undertaken.

RECOMMENDATIONS

1. **Improved access to KD therapy and transition to adult services:** many families 'had to fight' to access the KD and described the relief when they met a supportive KD team. Families need support with the anxiety of weaning from KD and transition to adult services.
2. **Better variety and access to KD foods:** both prescribable and shop bought would be welcomed.
3. **Ongoing support from charities and the KD team:** Matthew's Friends, the Daisy Garland and Young Epilepsy, all credited for providing practical and emotional support for families.
4. **Regular social education:** Group keto cooking sessions were invaluable for families.
5. **Peer mentoring:** Most families would welcome a 'keto buddy', someone experienced with the KD. Online forums go some way to providing this but 1-1 is preferable.

Results - Themes and Subthemes

EPILEPSY IS ALL CONSUMING

Explores the impact of epilepsy on the family, the uncertainty and the search for answers.

Subthemes

- Impact on the family
- Uncertainty of epilepsy
- Fight for my child

If you asked what the impact of seizures on our life was, it was our life for quite a number of years. (FP10)

It kind of changes the way that you attack everything. It's kind of a grieving period of, well our lives are not going to be the way we thought they were. (FP11)

It's [KD] still very much the poor relation, in my view, it feels like the diet's not given an even - that its not an even playing field (FP1)

Everything's a battle, that's one thing we learned. Nothing is easy, nothing's straightforward (FP14)

A WINDOW TO NEW OPPORTUNITES

Explores the motivators for KD therapy and positive outcomes for the family.

Subthemes

- Hopes and expectations
- No longer a passenger
- I've got my child back

We went into it hopeful.. we'd tried the strongest drugs... they hadn't worked, we were kind of like maybe it will work, lets give it a try, we've got nothing to lose (MP1)

KD was something we could do. It would take work and effort, whereas everything else was just kind of out of our control... give you a bit of control in the scenario, that you've got no control over (FP11)

it was unbelievable, because we had him back. He was acting like a normal kid. We removed the helmet in a month, and he was doing just great (FP5)

It's almost opening the window up to him learning new skills that he never had that possibility before..the KD has given me a bigger window of hope for there's still options out there for him. (FP12)

THE REALITY OF KD

Explores day to day life with KD and how families adapt.

Subthemes

- KD can be challenging
- Evolving KD mindset
- Support network is crucial

Socially it's awkward, financially it's a bit hmm, shopping's a bit hmm, but at the end of the day there's no chocolate bar out there that's worth going back to how he was. (FP7)

It's challenging but it's got easier as time has gone on .. for the first 3 months I used those menus religiously to stick to the parameters and now I just use a mixture of all the menus (FP16)

We've probably had one of the best experiences of X hospital that you could ever have (FP9)

Matthew's Mum was brilliant, when we were still trying X with breakfast cereals and we couldn't get any... she was fantastic. She literally posted me a whole box. (FP2)

the level of support I've had from Daisy Garland is another level, ...they will always respond, Daisy's Mum, they go over and above (FP14)

LOOKING TO THE FUTURE

Explores the factors that would make KD easier for families.

Subthemes

- Enhanced awareness and understanding of KD
- Support and education
- Variety and access to KD foods

....we have got no intention of taking him off it [KD] if I'm honest. The thought to that would be frightening. We've just got to make- you manage, don't you?...I've already told them [KD team] don't talk to me about it (FP19, MP2)

I think having more access to ready meals, stuff that you could buy off the shelf, or on prescription, ideally on prescription (FP8)

I found these [KD cookery days] beneficial, just to meet other people..you feel quite isolated and nobody else really understands (FP6)

So to have somebody - yes that's come on, keep going, it's worth it, and we've all been there, you'll get through to the other side..that actually has the experience of starting the diet...That would have been really good (FP13)

Ethical approval (London-Surrey REC, 19/LO/1680)

¹ Faculty of Health, University of Plymouth, Devon, UK.

² Developmental Neurosciences, UCL - NIHR BRC Great Ormond Street Institute of Child Health, London, UK

³ Matthew's Friends Charity & Clinics, Lingfield, Surrey, UK.



We extend a big thank you to the parents who shared their experiences



Take a picture to download the poster and visit our study webpage

