

Living with ADHD in Herefordshire

Name: Ellie

Gender: Female

Age: 46

Lived Experience Journey: Eliie & her son

Ellie spoke to us about her experiences and journey she has been through with her son ANON.

For context Anon is now 17 years old, but Ellie remembers that ANON was round 3 almost 4 years old when she realised that he was 'different' in his ways to her other children (Ellie has 4 other children).

Ellie noticed that ANON had what she now knows to be hyper focus and hyper infixation – she noticed this through his play and ability to interact with his siblings at home.

Ellie initially tried to seek help from her GP, but she recalls they didn't really entertain this and felt that he was too young and could just be his development progression. Ellie said as a parent that had never experienced this before, I kind of believed what they told me and continued ANON with mainstream schooling and processes.

As time developed in his first year at school issues kept happening – one of which Ellie recalls was a safeguarding issue (she didn't want to expand on this at this time) but due to this she moved ANON from a larger primary school in Hereford city to a smaller rural primary school. Ellie says she felt this did make a big difference at the time. At

the larger primary school she said the school basically blamed her as she had recently become a single parent. The smaller rural primary school though recognised within the first term ANON was there, that he had some kind of neurodiversity and suggested he was referred for a test.

Ellie then contacted her GP again and she was able to get the referral as she had the school evidence and referral suggestion – she said this process for her and ANON was actually very quick and she had referral made in the February when he was 6 years old and had diagnosis by the May.

This enabled him to get his CAHMS support and SEND provision through the school relatively quickly.

Ellie highlighted again she feels that the smaller schools have a better ability to know children on a more personal level and therefore have a better ability to recognise neurodiversity's. She also adds she has seen and heard this from other parents with ADHD children she knows.

The smaller school supported ANON well, tried to help with quiet rooms, flash cards for communication even before the EHCP had been activated as such. ANON was also given 1-2-1 support.

Ellie says she felt that as a parent she has learned to be adaptable and think about the approaches she takes to support ANON and enhance his learning – she said ANON also was diagnosed through further testing instigated by the school with ASD and anxiety. Ellie did feel though that the ADHD main test should also take this into account and look for these other traits and conditions – as it is stressful for a child with ADHD to keep going for these various tests.

ANON managed through primary school but as he went into secondary school education, Ellie noted this was when real issues started and his mental health suffered more. Ellie feels secondary

schools aren't well equipped to deal with ADHD students that well and although they may offer 1-2-1 support their support programmes and ways of working with these children isn't suitable. She also found by the time ANON had got to secondary school CAHMS had become very unreliable and getting an appointment to see them was becoming harder and harder – after mid to end of primary school they only saw one CAHMS doctor in 7 years.

At this point in his first year of secondary school Ellie decided to pull him from mainstream education and home school ANON mainly to support better mental health for him.

Due to the irregular contact with CAHMS medications were all over the place and getting them became harder as you often need a review to make sure the amounts are correct and still having the right impact. Medications were on a rolling prescription that they could get direct from GP but these were often delayed or not sent or in recent times not available due to UK shortages - so often ANON missed medications as they physically didn't have them. Ellie reports this situation isn't any better now and getting meds is still very hard.

Over recent times medications have been arranged through a ADHD nurse and a locum GP.

Ellie said locally home education support was poor and there was no real way to go with this – so she joined national groups and platforms for home education and tailored what she did with ANON using his interests such as cooking to support his learning interactions. This boosted his confidence and reduced his anxieties.

As a result of this home education ANON has recently started college three days per week and is doing cooking courses. Ellie believes the home education really changed ANON positively, his ways, his social confidence and his mannerisms which has enabled to get to college.

Now as ANON switches over into adulthood – Ellie recognises the different challenges he will face and she is planning for these to support him into work etc.

The impact of the issues with medication is still massive and can change his ability to sleep and focus so the inconsistency in getting them really messes with his opportunity to do well at college she thinks. In Hereford city she can only currently get ANON'S meds from one pharmacy.

Ellie recognises that as he moves into adulthood the options for support and groups don't seem to exist the same nor is a network of employers that support work placements for example for those with ADHD – she thinks this locally would be a huge advantage and a platform like the Talk Community Directory could be a place to have this.

Ellie is concerned that ANONS access to a mental health nurse/doctor will also decrease as appointments to see them now are greatly reduced due to capacity and resource so she worries about what chance he will have as an adult.

Ellie told me how she has battled all of these years to keep ANON in the 'right direction' from not being easily led into the wrong groups and with the wrong people who would take advantage of his ADHD – she said raised awareness at schools with other non-neurodiverse children would help.

Ellie also recalled back to when ANON was around 5 she was refereed to the Triple P parenting course – and Ellie recognises whilst the course isn't bad its also not right for ADHD parents but a tailored course would be and she thinks lots of parents would be happy to do this online. She said on the course she was on 9 out of the 14 parents on there had a child with ADHD.

She said that she has learnt with ANON that keeping a strict routine is vital to reduce the impact on all their lives as a family and support ANON to do his best in an environment that suits him. Likewise, she said life skills and support for helping learn patience and quiet time benefits would be useful and others such as preparing for events and trips in advance.

Ellie said that through doing these things she has reduced the impact on their lives as a family – but ultimately the time she has taken to do all of this for ANON means she has had little time for herself and hasn't been able work. Now because of this she will find it hard to get into work she wants. She thinks these are the more unseen impacts of living with someone with ADHD.

Ellie suggests that school communities of parents could lead support groups that you could stay with as those children grow up and move into adulthood, so you have a network of support and the children also know and support each other through the stages.

Ellie felt that Herefordshire could do more to support individuals and families – which she feels would have a huge impact and reduce the other knock affects that can happen to children with ADHD if not supported correctly such as anti-social behaviour in communities and skipping school etc.

Some of her thoughts were around;

Better medical facilities – making appointments and the environments more suitable for those with ADHD and supplying information in a way that enables them to understand – such a short bullet points and support planning for short periods ahead.

Using social media platforms locally for support. Such as closed groups sharing tips and advice for adults – this can really help those transitioning into adulthood.