

# NEURO KEY

An Alliance supporting people  
with neurological conditions

## FOETAL ALCOHOL SPECTRUM DISORDER

‘Unlocking minds and opening doors’

Open Door series by Neuro Key



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# Foreword

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Since inception Neuro Key, the working name of the Charity, Tees Valley, Durham and North Yorkshire Neurological Alliance, has harnessed lived experience as an educational tool to improve service delivery and professional understanding of not only the common threads between neurological conditions but also the complexities. From enabling participants to take part in research, delivering lived experience seminars, making sure people can respond to surveys and strategic consultations or supporting people to lead the operational direction of the Charity, we are passionate about our social purpose.

We promote a culture of mutual exchange to broker common purpose across all neurological conditions. More importantly, we do not define by the deficits a condition may impose on people's lives. We concentrate on the value of lived experience to professional knowledge and skill, the contribution to the evidence base and for people themselves to share and learn from each other. By supporting people to be more confident in knowledge sharing and cooperation across social divides we sustain a well-informed neuro community to improve self-management skills, neuro-literacy and social capital.

We foster collaborative working partnerships to respond, support and sustain a high customer service focus to encourage creative problem-solving and efficiencies by reducing risk and crisis. We strive for excellence with agreed standards and outcomes.

Our Open Door series of booklets has been developed to acknowledge the challenges of living with a neurological condition that is misunderstood, subject to media-driven or political myths and is neither prevalent nor the focus of national publicity campaigns.

Foetal Alcohol Spectrum Disorder (FASD) occurs through pre-natal alcohol exposure which causes a permanent brain injury with a neuro-behavioural impact. Some people may have identifiable facial features but for the majority it is largely invisible. There is evidence of the brain injury across many domains such as attention, memory, social skills, receptive and expressive language, fine and gross motor skills, hyperactivity, difficulty with abstract concepts. There may be associated conditions such as autism, ADHD, attachment disorder and poor mental health.

One of the motives for this booklet is that children with conditions like FASD become adults and their complex needs are often misinterpreted by health and social care personnel.

The following stories are all real life narratives written by parents and kinship caregivers of young people living with Foetal Alcohol Spectrum Disorder. We have adopted fictional names to protect their identities.

## **NEURO KEY**

December 2020

# Melanie's story

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## The Journey

Most people have never heard of Foetal Alcohol Spectrum Disorder (FASD). Those that have often think of it as rare, misunderstanding the cause and the impact of this life-long, devastating, but preventable condition.

In some ways FASD could be considered similar to Autism in that it presents with a range of difficulties. It is not unusual for a child to be diagnosed with Autism when in fact they have FASD. Sadly, there is a perception that only an alcoholic mother can give birth to a child with FASD. However, unlike Autism where the brain is working differently, FASD is a consequence of a woman drinking alcohol during particular points in early pregnancy resulting in irreversible brain damage of the infant. FASD is the biggest cause of learning disability today and it is the unseen features of FASD that make it such a debilitating condition.

The majority of babies and children with FASD find themselves in the care system due to their birth parents being unable to look after them. Consequently, it is adoptive parents, foster carers, and kinship carers who have the task of caring for these children. Ordinarily, being a parent is challenging, add in caring for a child with a complex disability and life becomes very grueling.

I am an adoptive parent. I was told by social services that my daughter's birth mum had not used drugs or alcohol during pregnancy.

Before meeting our daughter we were told she had been born with a congenital cranial disorder which was cosmetic and would not in any way affect her development. Her differently shaped skull would not be noticeable once her hair grew. We had been told that she had been a difficult baby with early feeding problems and had been frequently in a bad mood making it hard to settle her but that had been resolved.

When we first met our daughter, I remember thinking how small she looked compared to the photo we had been shown prior to matching and more importantly, how silent

she was. She was 14 months old and although we had been told she had normal development, during the first few hours we were with her she did not babble once. I was convinced she must have a problem with her hearing.

Despite having some unusual facial features, an assessment at Great Ormond Street Hospital including genetic testing, showed that our daughter had a normal genetic profile. Unable to speak she was later diagnosed with an oral motor delay. We learnt sign language and attempted to teach

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Our daughter has not met the inflexible, formulaic criteria set by public services and yet clearly she has complex needs

this to our daughter to communicate. Months of waiting for speech therapy followed, intervention from play therapists through Portage and regular appointments with Pediatricians, we were told she may never speak and needed to be educated in a "Signing" environment. Our daughter was not deaf so our local education provision would not accept her.

Our daughter has not met the inflexible, formulaic criteria set by public services and yet clearly she has complex needs.

We undertook our own national search for a suitable school.

We relocated 250 miles from our family to North East England to ensure our daughter had access to a school where signing was embedded in the environment and speech therapy was onsite.

When our daughter was 5 years old she finally started to speak and it became clear to the therapists that her memory did not seem to work normally. Also, she would achieve a goal but when asked to repeat the task a week later had forgotten how to do it. At this time she started to display

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unpredictable behaviours, would get suddenly aggressive and needed to have 1:1 support at school due to her impulsiveness. Her concentration was limited and her social skills were markedly delayed. Another assessment diagnosed our daughter with a learning disability which was a huge shock given how speedily she had learnt to sign and was competent with things like with jigsaws. At this time I came across a number of articles in Adoption magazines about FASD. The first time I read about this condition, I knew this was the reason behind my daughter's difficulties. It was like I was reading about her. When I raised this with professionals, we were told as there had been no antenatal history of alcohol abuse this condition would not be considered let alone confirmed.

We were referred to a regional specialist who added Autism to the growing list of diagnoses our daughter was acquiring. We had increasing difficulties at home managing her unpredictable and at times aggressive behaviours. We were referred to Child and Adolescent Mental Health Services (CAMHS) at this point but because our daughter could read we did not meet their criteria for accessing support from the Learning Disability team. We were convinced there was a sensory issue causing the difficulties with our daughter's personal care but were unable to access an assessment.

Frequently, our daughter has not met the inflexible, formulaic criteria set by public services and yet clearly she has complex needs. Repeatedly, we have been told support is not about a diagnosis but this has not been our experience. I had almost given up on us getting to the truth about our daughter when a TV programme reignited my determination to do so.

The programme detailed new research techniques being used to diagnose FASD using 3D facial analysis. I contacted the specialist and found I could volunteer our daughter to take part in the study. We made the journey to London where our daughter had 3D photos taken and these were compared with a database. As a result of this analysis it was recommended we get referred to the National FASD

specialist, Dr Mukerjee for clinical diagnosis. Armed with the report from the Institute of Child Health in London I visited our GP for a referral. I was told this request would have to be sent to the North East Commissioning Service for funding. Funding was denied. My husband and I had no disposable income. We had given up our jobs to take care of our children, all with complex needs.

Undeterred, I emailed Dr Mukerjee and was offered a free telephone consultation. During this call, I was given the name of a pediatrician in our region that specialised in FASD and returned to my GP for a referral. No special funding was required so, after six years of struggling to be heard, we had an appointment with a person who would be able to end our turmoil and provide some much need care for our daughter.

We attended the appointment armed with a file of documents including speech and language reports, CAMHS reports and the new 3D facial analysis information. My daughter has an enormous number of difficulties including a significant learning disability, expressive and receptive language difficulties, sensory processing problems, frontal lobe dysfunction resulting in impulsiveness and poor regulation of behaviour. She also has a cranial birth defect, vision impairment and oral motor delay. She has limited awareness of danger, frequent sleep disturbances, unusual eating patterns, poor social functioning and poor memory. We were given a diagnosis at the end of our consultation. The doctor was shocked that our daughter had not been diagnosed sooner as she was 11 years old. There were so many obvious clues in how our daughter presented yet no one had linked them together.

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## Our daughter

Our daughter needs 1:1 support at school and when out in the community at all times. She needs a high level of assistance to meet her personal hygiene and other needs. She cannot gauge when the bath water is too hot and cannot be left unsupervised. She would not turn the taps off as she cannot anticipate consequences of the bath overflowing. She often does not like the sensation of being touched for help with washing. I regularly have to cope with being bitten, pinched or kicked. She will refuse the routine of hair washing hair and will be aggressive when her hair needs to be rinsed. She may refuse to get out of the bath until she is ready. She needs assistance to dry but owing to a lack of inhibition, she may come into the living area with no clothes on.

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## We were labelled as part of the problem, not experts

She struggles to verbally express her thoughts and feelings so does so through her actions, which would commonly be interpreted as aggression. She wants to engage with the world,

she is very sociable but the world doesn't know how to engage with her. This makes me sad and fearful for the future. Our daughter has a wonderful smile. She can read and write but has limited understanding of what words mean. FASD is a cruel condition causing a rollercoaster of difficulties which are often misunderstood.

Our daughter has accomplished many personal achievements over the years and I am incredibly proud of the young woman she is becoming. However, she will never live independently, travel the world with friends or have her own family. I grieve on my daughter's behalf for these losses and at the same time I am proactive in advocating every day for the support she needs to maintain a good quality and meaningful life.

We were labelled as part of the problem, not experts.

I have given up my nursing career, my social life and my way of life on the journey to ensure my daughter's needs are met. It took 2 years for social services to agree to provide a support worker to come and get my daughter ready on school mornings. I was physically and emotionally broken at this point and was asking for help but nobody was listening. I had social services disagreeing over whether her assessment should be completed by the adoption or disability team and no support offered during the months it took to reach an agreement and then undertake the assessment. We paid the cost of care but as always the cost to family is not just about money. At the end of a complex process where we were labelled as part of the problem rather than experts on the needs of our daughter, we received no support. We were damaged by our experience with social care and had little faith in the institution which should be there to help. It is really hard to ask for support. You feel a failure asking for help. The impact on carers' physical and mental wellbeing is profound when you are subject to pre-conceived ideas and blinkered thinking.

## The outside world

It was a relief to get the diagnosis but our experience highlights the lack of awareness of FASD in the UK amongst professionals. As adoptive parents, we were disadvantaged by not having accurate antenatal information and this prevented an accurate diagnosis.

Individuals with unidentified FASD are often labelled as difficult or naughty people with the perception that they will not do things when the reality is they cannot do things because of the damage to the brain. With the brain damaged, functioning is random, what can be done one day may not be achievable the next. Lack of support increases vulnerability for the carer and young person alike and makes it difficult to make accurate decisions around promoting safe independence. It is well documented that

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many adults with FASD end up in the criminal justice system as a result of their impulsiveness and vulnerabilities.

The lack of specialists leaves children undiagnosed and floundering in their everyday lives, especially at school and with their mental health. Local statistics are inaccurate which means commissioners cannot plan for the needs of this complex group of individuals. The impact on resource to support these individuals in health, education and social care in addition to supporting caregivers is evident, but unquantified. A young person should be supported to adapt to a purposeful life.

Last year, the Local Authority decided to remove the escort from our daughter's school bus without warning and without a risk assessment. Bearing in mind she was schooled in the next Borough, this left us unable to use the transport. For us, it was a safeguarding issue and we were not prepared to put our daughter at risk. It took us fourteen months to resolve this.

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I feel betrayed

Inadequate understanding about our daughter's care needs put a huge strain of us as a family unit not only in having to undertake the school run ourselves but in challenging the Local Authority. Luckily, a new manager gave us some support to help resolve the problem.

Whilst this was happening we were also informed that our Adoption Allowance would cease due to changes in policy. The Local Authority suggested I seek employment instead. Despite being fully aware of our daughter's care needs, multiple diagnoses and impact on my ability to seek employment, the payments ceased. I lost the motivation to challenge this decision due to the demands as a parent carer and the impact on my already shredded mental health.

I attempted to get some help by having a Carer's assessment. Becoming a full time carer is not something I imagined when I decided to adopt. The approved

assessment took ten months to action just 2hrs a week support. Despite being a statutory duty, the Local Authority had no process in place to provide support to parents of children with disabilities. As a carer of a child with FASD, I am advocating for both my daughter's needs and my own. I am frequently frustrated and feel betrayed by the lack of appropriate support available and the attitudes of people I have to deal with.

Caring for a loved one with FASD is challenging and could definitely be made easier by professionals being more supportive. The recognition that professional support should be holistic and family centered would be a great step forward.

# Davina's Story

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## The Journey

I adopted two girls aged 13 months and 5 months, when the placement started and they are full blood sisters.

My eldest daughter was born 6 weeks early weighing 4lb. Apart from a little jaundice appeared well and was discharged into foster care a few days later. My youngest daughter was born 1 week early and again was fit and well at 7lbs and was discharged into a different foster care placement the next day.

When reading birth family records there was nothing untoward, the pregnancy had gone well and social services were involved with the parents as the plan was to remove the children immediately as previous children had been removed for their own safety. As an adopter this was great news as nothing bad physically had happened such as neglect or abuse. I'd had my adoption training hearing horror stories this filled me with hope knowing they hadn't been starved and that they hadn't witnessed abuse.

My eldest daughter was a quiet baby that was struggling with milestones, at 13 months she wasn't able to sit unaided, still ate mashed food as she would choke on lumps, wouldn't drink milk and never seemed thirsty. When crawling she would hold one leg under body. She liked lots of walks her foster mum told me. What I found rather abruptly was she meant was she didn't sleep unless cuddled or walked in the pram for miles if settled in her cot she would scream to the point of hyperventilating. We bonded well as she wouldn't leave my side, I couldn't leave the room without her screaming. I soon learnt to do everything one handed as she was always on my hip clinging on for dear

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Social services were confident that her developmental delay was because she had been in care

life. Eventually she was able to sit for longer periods and eventually stand, by 17 months she could walk a few steps, her eating was slowly progressing to small lumps but she would still struggle to take in enough liquids and so would be constipated. She didn't say many words but would swallow air constantly like a frog noise. At this point I was already thinking there were some issues but social services were confident that her developmental delay was because she had been in care and it was just attachment related. We went to an appointment as my daughter's head was very small and she had a follow up appointment, I asked if this was a sign of any problems to which they reassured me it was just who she was and so we were discharged.

After my eldest daughter had been with me for 3 months, her sister arrived. She was 5 months old already being weaning as she was drinking so much milk, sitting and babbling well and meeting milestones, weighing in at 21lbs compared to my eldest daughter only being 20lbs.

The younger girl was thriving, she went in her cot awake and settled well and was actually helping to bring the eldest girl on as whatever the younger one had, the older one wanted. They would drink the same juice, the eldest would want the youngest girl's food and although the eldest would copy trying to crawl and starting to make more sounds towards talking, she did not like the younger girl sharing me and would get very cross at having to share me.

Time went on and growth wise the girls were like twins and so that's how I treat them. My younger girl was doing so well but obviously the older girl was still very behind with her development. We had Speech and Language Therapy involved and sessions with Portage in preparation for school. The eldest girl was showing more challenging behaviour, she would have long tantrums about getting dressed not wanting to take clothes off and not wanting clothes on. Everything had to be done slowly with lots of warnings what was happening next, she was clumsy bumping into things and falling. By the age of 4 years I was researching Dyspraxia and asked to be referred to the

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school doctor. My youngest daughter was ticking along nicely with no issues as such compared to the eldest girl, she was very easy going.

The light bulb moment, I was watching an American forensic program where they were doing a post mortem on an adult, the brain was very small, then they looked at the creases on the man's hands and his facial features then

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Although the GP was very helpful she hadn't come across FASD

went on to discuss how he had Foetal Alcohol Spectrum Disorder (FASD) They listed traits and behaviours that was exactly the same as my eldest girl. I went straight onto my computer to research FASD and found so much information and realised this must be what her problems were. The next day, I had the doctors' appointment when she completed developmental assessments showing the problems with her delay in motor skills, behaviours, speech as well as looking at her growth. I mentioned I suspected Dyspraxia but then wondered about FASD. Although the GP was very helpful she hadn't come across FASD and explained I would need to find out more about the birth mum as there was no information about this in the records. Referrals were sent off for our children's developmental services to help with Occupational therapy for motor skills and the developmental delay. Although usually dry in the day my eldest was still having 'accidents' and always wet on a night, as well as the terrible nightmares and not sleeping.

I contacted social services to ask if they could find out more information from the birth mum which they were happy to try as a few years had passed from removal it was hoped the birth family would be more forthcoming with information than they were at the time of adoption. Within a few weeks I had the information. The birth mum had drunk lager most days of all of her pregnancy's as well as smoked. At this point, I felt some relief at being nearer to answers but

hadn't really fully understood what this meant for our future. I went back to the doctor with this confirmation of alcohol consumption and between us we looked at the eldest girl's dysmorphic features and between us realised that she had FASD and so a diagnosis was given in 2010 at the age of 6years. I felt a weight had been lifted, my mum thought I was strange but to me knowledge was power now I knew what was wrong with her. I could research and learn how to help her best and everything would be fine. By this point school was increasingly hard for her. She had passed the learning-through-play bit in school and now was expected to conform and sit for longer and learn but she couldn't cope.

I knew her so well, I could see by looking at her what sort of day she had had. The school tried their best but unlike many disabilities, you cannot see the brain damage and how it manifests in her. Her memory would come and go, she would shout out inappropriately, she had no understanding of personal boundaries and would want to hug and kiss everyone including virtual strangers. She had no sense of danger or safety and would not realise when she was hurt as she did not feel pain properly. She had to be told to eat and drink as she wasn't hungry or thirsty, she would only wear certain clothes that has to be very soft and tight fitting. She needed 1:1 in school for her safety and others. Then it would be home time and that's when it starts. She would literally look over her shoulder as we would leave the school gate to check no teachers were there and let rip she would try to run away whilst shouting and screaming with no real content as to what the problem was she would climb up trees, tennis court netting anything to escape, she was on sensory overload. My daughter cannot say how she's feeling.

## The outside world

Following my eldest girl's diagnosis I had the 'bad mother' moment when the information also confirmed that my youngest girl had been subjected to alcohol consumed when in-utero. As the paediatrician accepted she had little

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knowledge of FASD we had waited to see another doctor Kate Ward at Airedale Hospital. My eldest daughter's growth had slowed and I was unsure what help was needed for the girls. Kate confirmed immediately that both girls had the full facial features associated with alcohol consumption. The eldest girl has the most acute damage but as the youngest was still young she did not appear as affected. Compared to the eldest, meeting milestones appeared fine. So, I left with both girls confirmed with lifelong brain damage and

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## Referred to Child and Adolescent Mental Health Services (CAMHS) for the fifth time

lots of referrals being sent off for various therapies but basically, I just had to get on with things. The eldest received some therapy for motor skills to help with her strength, speech and language therapy. The younger sibling has received some speech and language therapy.

As the years have progressed, both girls have a dose of melatonin to aid with sleep. Although the majority of time this works there is still a lot of nightmares and days when the medication doesn't work. The eldest has been referred to Child and Adolescent Mental Health Services (CAMHS) for the fifth time recently, as she gets older her violence and aggressive meltdown's have intensified, the slightest thing can trigger these and usually she aims her anger towards her sister. There have been some sessions to try to help her to understand her anger but unfortunately the nature of her brain damage is that she isn't able to regulate her anger or understand it is happening and it is literally 0-100mph with no time to intervene from me. I literally have to restrain her and ride out the meltdown to keep her and her sister safe. As she gets older and stronger this is becoming more challenging as she can knock me over now and do more damage. Unfortunately, the eldest hates talking to people so she puts on her brave face and say what she thinks

they want to hear at CAMHS sessions then erupts after we leave because she has missed school or she didn't want to go. For the last three referrals, I have asked for medication but I was told they need to assess her more. There isn't any medication they feel would suit her even when I have suggested names of medication to help others with FASD and ADHD or Autism and anger problems. Unfortunately in my area, there isn't a lot of knowledge of FASD and CAMHS seem to be really stretched. We've also seen them regarding the younger girl and her anxiety that has developed over time. Although she was able to participate in sessions more because her short term memory is badly affected, she wasn't able to retain and recall information to try to help with moving forward. She is at special school now which has relieved some of her stresses.

My eldest girl is now 13years with a diagnosis of FASD, Attention Deficit Hyperactivity Disorder and sensory dysfunction. She has poor long term memory, developmental delay, traits of Oppositional Defiant Disorder (ODD), Autism and Obsessive Compulsive Disorder (OCD) and is like a 6 year old in many respects dealing with day-to-day life. There are days were she regresses and acts like a 4 year old. She is awaiting a referral for CAMHS again regarding her aggressive meltdowns. She takes melatonin each night along with the contraceptive pill to help with periods as she started puberty at 10 years old.

My youngest is 12 years old now, a diagnosis of FASD with some developmental delay but is progressing well in special school. She has undiagnosed sensory dysfunction, poor short term memory, traits of ODD and suffers mainly with poor mental health, being very upset even depressed and has panic attacks. She cannot cope with any feedback if anything other than positive as she takes everything to heart and has very low self-esteem. She is under the care of a gynaecologist as her periods started just over a year ago and have been so intense she has been to hospital. She takes three types of medication as her periods can last a month and have caused anaemia they are so bad, alongside melatonin to help with sleep.

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## My request is that carers are able to be the child's advocate and as their 'external' brain

Within our home, I provide a loving, safe environment that is very much about changing the environment not the child. I am greatly concerned for the future of my children in a society that doesn't see their disabilities. I count myself very lucky that we can go for days

out and attend certain functions if I have prepared them first. They are very polite and well mannered. However, as they are growing into young ladies it concerns me they are still not receiving support to help them deal with the negative behaviours that we all know into adulthood can create massive problems with mental health and possibly with the judicial system. My request is that carers are able to be the child's advocate and as their 'external' brain. I beg professionals not to have to see 1st hand the behaviours as these can be very clever children hiding their issues to conform. I have listed a normal day in our house that obviously isn't seen to others trying to believe the polite young girls smiling at them are actually crumbling inside.

## A life in the day

- 6.30am start to wake girls for school, gently rubbing legs, opening blinds to abrupt waking can cause flight mode and cause a meltdown. After 10minutes grumbling about not wanting to go to school and verbal abuse starts, I walk away.
- 6.40am go back into bedrooms to continue rubbing legs taking about positives of the day to encourage girls up, more grumbles but gradually get up by 6.50am.
- once seated on sofa with Peppa pig on the TV, calm resumes.
- I put clothes out on beds. For the eldest girl, these are the same shirt skirt and thread bared cardigan everything has to be soft no seams, certain sourced socks and pants of a certain colour, the same tired bra with no underwire that is desperately needed.
- 7am enough time has passed I can discuss breakfast, choices are a no go and so two choices only are given. The eldest chooses something crunchy whilst the younger girl goes for plain soft foods, breakfast is spent sat on the sofa, going to the table would be another trigger for a meltdown.
- 7.30am girls are warned we need to get dressed.
- I get dressed and sort out school bags ensuring planners and drinks are in them.
- 7.40am girls are more forcefully told we need to get dressed. The younger girl has help washing and getting underwear on then dresses herself.
- The older girl will not have her sister anywhere near her and so will go to bathroom once the youngest has finished. The eldest needs help freshening up and has to have placebo cream on her private parts as they hurt (sensory issue). Her bra straps have to be slackened to put her bra on. I tighten them once on or this will cause meltdown and then takes clothes off again. The eldest will then put her shirt and skirt on herself.
- 7.55am the eldest needs me to put her cardigan on as the sleeves must be smoothed over her shirt sleeves there can be no creasing or a meltdown and undressing will ensue.
- 8.00am both girls put shoes on. I must prepare the eldest girl's laces as they must be equal length or they will be launched at me with swearing and refusal to wear them.
- 8.05am reminder to brush hair and teeth usually takes 3 reminders.

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- 8.10am taxi arrives to take them to school. At any point the eldest can recall an event from the previous day or what is happening on that day that can cause her to seek an argument about not wanting to go to school whilst also getting angry that I would dare suggest her not going.
  - 4pm taxi arrives door is flung open and a tirade of information from both girls simultaneously is thrown at me, a friend did this, a teacher said that.
  - 4.05pm snack and drink are given this can calm things or depending on the day a meltdown can occur if the younger girl looks at her sister the wrong way and then she swear and shout trying to hit her younger sister. The younger girl panics and laughs which infuriates her sister more and the older girl has to be held back whilst her sister is asked to go to her room for safety.
  - 4.40pm usually enough calm is slowly resuming. The eldest has been moved to her bedroom to watch a favourite meerkat movie or do some colouring, she's exhausted.
  - Depending on how bad things are this may be it or the eldest may start again if her sister talks too loud or dares to say the wrong thing to me. This can go on for hours with the eldest girl slowly giving information of her day, a friend said this or someone said that, someone talked to her boyfriend or her boyfriend wasn't out at break time.
  - 6pm tea is finished and time to start bedtime routine, I bath alternate days as this is a cause for a meltdown if water gets near eldest girls' ears, or if she has to wash her hair. The younger girl just refuses as she hates washing and doesn't see the need.
  - 6.30pm after several reminders the eldest is in the bathroom, she has to be freshened up and placebo cream applied again before her pull ups go on as she still wets the bed, once finished, the youngest will get herself ready for bed with several reminders about washing with soap and brushing teeth.
  - 6.50pm girls are ready for bed, have their milk and medicines then off to bed, at this point as with most children the recall of all the day starts, eventually this is complete. The eldest then has placebo ear drops as her ear is hurting, music on, lights off hugs and kisses and by 7.30pm I'm out of the room.
  - 7.35pm the tag team starts, this hurts, that hurts from the older girl whilst her sister usually dwells on the worries of the day and what tomorrow may bring.
  - 7.50pm usually have settled or it escalates to arguments because the eldest is cross and the youngest has to go away because she is talking. This can erupt into full on meltdown but by 9pm both are usually in bed settled.
  - 11pm usually when the eldest starts shouting and screaming in bed usually very upset and gentle soothing helps this, can happen a few times in the night.
  - 1.30am usually when the younger girls' nightmares start and she ends up in my bed when the panic sets in.
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# Sandra's Story

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## The Journey

My nephew came into my life as the cutest blonde 3 year old I had ever met.

Born to a heroin addicted mother, he was taken into the care system at birth, living with the same loving foster parents up until his adoption at aged 3 by my sister and her husband.

My husband, son and daughter bonded with him very quickly, but sadly my sister and her husband struggled as his younger brother was in the throes of withdrawal from heroin and took a great deal of time and energy. His younger brother was just 4 months old on adoption. My eldest nephew was always and still is considered as trouble, the naughty child, the hardest teenager, to the present day a 20 year old child.

I was always called on by my sister particularly after her divorce when my nephew was 9 years old to be the back-up bad cop. Having to relentlessly talk to him about his behaviour, by aged 11 he was the proud owner of his first ASBO. As a mother, my gut told me there was more to his actions/reactions than simple naughty child problems. It was evident that my eldest nephew found sharing attention from my sister with his younger brother very difficult. With his adopted dad no longer on the scene, my nephew was left to his own devices.

At the age of 15, an eruption of constant quarrels, several more ASBO's and concern for the safety of his younger sibling, my sister called social services. She made it clear that she could not cope and the suggestion at the time was assisted living within a unit for 15-25 year olds. A family discussion led to me offering my nephew a home within my family although we did not quite expect it to happen as quickly as it did. We had no time to prepare as a situation on his 16th birthday resulted in me bringing him home for the night. In fact, that was the start of my journey against everyone else.

At the time, my son was 21 years and my daughter 19 years. We lived in a small 3 bedroom house. My nephew slept on my pull down sofa in the dining room, the kitchen and bathroom only accessible through the dining room. You can imagine that life was a struggle given that this is where he remained for 20 months, prior to a loft conversion to create another bedroom.

Living with him brought various emotions to the surface. My son constantly moaning that his socks or boxer shorts were missing, my nephew denying he took them but would blatantly walk past wearing them.

Silly annoying things soon became increasingly irritating, squeezing the toothpaste from the middle of the tube and wasting most of it down the sink. It was the same with shampoo and shower gel or leaving windows wide open after using the bathroom even in the early hours of the morning. The bathroom is on the ground floor and he would take a bath at 2 am because it was quiet. During the day we would encourage him to open the window to ventilate the bathroom. Thus, even at 2 am he followed the same instructions and went to bed with little concern or concept of safety for the home or family members.

We are 10 door keys later after my nephew has repeatedly lost each one. He wondered why we would get annoyed. The list was endless, losing money, wasting food, addictions to anything, street drugs, gambling, buying expensive shoes and clothes or watches. You name it, his behaviour for want of a better word wasn't normal.

Having brought two children through the teenage years I was well aware we had a problem. He simply had no awareness of consequence. His lack of understanding about responsibility, timelines and especially money management was becoming exhausting.

In the first 2 years of him living with us, my own health deteriorated badly but I was visiting drug addiction help centres, listening to what he had become addicted to and wondering where I had failed him. One day by the grace

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of god, I was introduced to a lady who was averse to the consequences of alcohol in pregnancy, thereafter a battle commenced, with everyone.

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## I felt my nephew had not been given a very good start and needed someone to fight for him

poor problem solving, often lost his temper, difficult in sleeping, significant startle response, the list went on and on, three pages of it, we filled it in.

She gave us a name of a top paediatrician in the country that specialised in Foetal Alcohol Spectrum disorder (FASD). Fast forward to the age of 18 and after asking our GP to refer us to this consultant we had a 100% diagnosis of FASD with a duplication gene, thereafter a battle with service-land began.

In this timeframe, with my health declining, my nephew turned 18years and the Social Services wanted to release him from the child services. By this stage my sister had opted out of any parental responsibility. I felt my nephew had not been given a very good start and needed someone to fight for him. My battle was hard with everyone, GP and Social Worker, his friends, his mother, my extended family, his place of work. Yes, he managed to get a job, my family support network consisted of either my husband or my children or myself taking him to work and picking him up every day, it was exhausting.

He would spend money quicker than he could earn it, his gambling addiction was merciless. In fact every addiction was bad, his confabulation of events extreme, he lost his wage packet so couldn't pay his way, he was sleeping at

Never had anyone picked up on all his behaviours until we came across this lady. We were offered some paperwork to complete, tick boxes mostly, explaining how my nephew would lie about the obvious, not follow through on instructions,

his mates, but a phone call the following day blew that out the water as he was sitting in a jail 200 miles away. He was vulnerable and anyone and everyone took advantage.

A bitter sweet moment came when we argued over his wasted money, more confabulated lies about his wages not being paid, but he had spent them. Ironically, he did go 4 months without pay working for a company that was sinking faster than the Titanic. He decided to move out of our house and move in with his 18 years old pal and the pals 17 year old girlfriend, sofa surfing I think you call it, after almost 4 years I think our boundaries were a lead weight to him.

He lasted 8 weeks, begged me for help because he was in debt with drug dealers, hungry, smelly, being taken advantage of by so called friends. I begged the GP for help but this resulted in antidepressants being prescribed.

Unfortunately, 4 weeks later he was better and didn't need them anymore, his way of thinking.

## The outside world

I skip to April this year when he changed jobs and moved into his new flat at the end of February. We had managed to get him a one bedroom flat in a very nice part of town which we decorated and furnished for him. On the day he moved in, a letter arrived from his consultant stating that he would never live independently. Silly, silly auntie, I should have listened.

Anyway, my nephew had a complete breakdown. He was spiraling down, drug induced behaviours didn't help and we hit crisis. Our first experience to mental health services left a lot to be desired. By now I was fully suited and booted in war armour and believe me, I needed it.

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## The 0-25 disability team kept insisting that he didn't fit their criteria

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At every opportunity, I tried to explain his condition of FASD when he was given Cognitive Behaviour Therapy (CBT) and given written homework. My battle with the service provider about cognitive impairment just didn't seem to get through. On 17th April 2017 was the day I declared war, his crisis was extreme. He was found on his living room floor having taken anything and everything available on the street he could get his hands on. After seven hours in A & E we were seen by the crisis team. We begged for him and ourselves for help, although he said he was by this time sick of asking for help. I agreed we had been through a great deal of different services, including 0-25 disability team who kept insisting that he didn't fit their criteria.

A mental health professional deemed him a drug addict and said there was no way on that day he would be admitted to the crisis hospital ward, despite my nephew saying he would hurt himself or someone else to get locked up, he wanted to be locked up. Safety in his eyes was being locked up. That day we went to a second hospital and that resulted in admittance for one week to a mental health unit.

He was released seven days later, having had a full assessment and deemed not to have any mental health issues but indeed, had full capacity and labelled a drug addict, despite our guardian angel advocate advising the Staff that the assessment wasn't the best method to fit his condition. The war continued as my nephew went downhill fast. I complained bitterly about his care and this resulted in him having two ladies call by his flat, talking to him for 1 ½ hours. On a good day, my nephew had a concentration span of 10-15 mins. This situation successfully turned into a massive crisis that very evening.

For those that would agree I fight my corner, bit between the teeth and all that but the straw that broke the camel's back came calling that day. The following morning, I made a phone call and spoke my mind. 'You asked him if he could wash himself, he said yes, tick for you, you asked him if he could cook, yes he said (hilarious as he is a chef), could he manage to go shopping, yes, yes, yes' he said. Then they left and we picked up the pieces,' do they think

I'm thick' he cried. He can wash himself I said, because I pay his gas bill for him to have hot water, he uses the body wash I buy and put in his bathroom. He cooks the food I buy and put in his fridge and uses the oven which works because I pay the electric bill. He comes shopping with me to pick his weekly food, chocolate, ice cream, £10 sirloin steak because he doesn't like anything else...

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### Yet again, the assessment says he can live independently

They listened, they worked with our advocate and the social workers asked me to pull back my support so they could see the wood for the trees. I pulled back and in this time they carried out assessment after assessment and still no care. I phoned and said it is going to be too late they need to conclude ASAP.

Tonight, I am at A & E as my nephew tried to take his own life. In his words he will never be normal, he has begged for help and they are taking too long, he doesn't see a future, it is too little too late for him he said. His job was hanging by a thread, it will be too late to retrain, no girlfriend, no future. He wishes to die. 'Why aren't they listening' he asked as my head is banging against the wall. He has been promised rehab in four weeks. Four weeks to him seems like four years.

By now, his FASD consultant has reduced his life expectancy from 34 to 28 years.

My nephew continued to spend money as if it gushed from a tap and the Department of Work and Pensions have agreed I manage his Personal Independence Payment as his 'Accountable' person. However, this does not count when following yet another assessment by Mental Health services they reasoned he had capacity to make decisions and manage money, just made poor choices and anyway, I am not the next-of-kin or have power of attorney. Another spiral down following a street drug binge and he was given a section order.

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Yet again, the assessment says he can live independently. Yet again, we go through the merry-go-round, 'only because I pay the gas bill, only because I supply what he needs to function'. Anti-depressants and anti-psychotics are prescribed, still no-one is prepared to take the bull by the horns and give him the psychiatric help and coping strategies he needs. After being placed on day release by a Mental Health Unit, he went awol for 36 hours. I fully expected to be identifying his body if or when they found him. The Police found him, exhausted, scared and hiding in his flat. He was so emotionally overwrought, mind you that goes for us both. Backwards and forwards we go, passed around services on the end of a bungee rope.

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It cannot be fixed by an assessment, or twenty

The latest crisis is more like ground hog day as we go through yet more assessments, told he has capacity and he has acquired more diagnoses to replace the FASD which they refuse to recognize. That is despite the Consultant who made the diagnosis telephoning the service. If it is a living hell for us, what is happening to this poor chap?

My nephew has an organic brain injury, his brain is broken. It cannot be fixed by an assessment, or twenty. He didn't ask for FASD, he has been failed all his life by people who think they know best or who have made promises they don't keep. At 20years old with services knowing he had a medically recognised addiction to heroin when he was born he is still waiting for some appropriate, responsive care.

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I am still fighting though probably running out of people to alienate

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I will continue to fight either till he gets the help or I lay him to rest

# Learning outcomes

	Be able to;	Relevant for
1	Identify the range of complex needs of FASD and suitability of assessment criteria	Primary care - GP's and staff NHS personnel Primary, secondary and special schools
2	Identify individual behaviours and variations	Primary care - GP's and staff NHS personnel Primary, secondary and special schools
3	Establish post-adoption advice and support routines	Primary care - GP's and staff Social Workers Mental Health teams Voluntary sector
4	Identify the support needs of caregivers and address the communication difficulties	Primary care - GP's and staff Social Workers Voluntary sector
5	Develop awareness of local community based referral pathways	Primary care - GP's and staff Social Workers Care support assistants Youth Justice teams Mental Health Crisis teams
6	Configure a co-produced care plan	Parent caregivers Kinship caregivers Primary care organisations Secondary Care organisations Mental Health teams
7	Establish awareness training	Primary care - GP's and staff Social Workers Care support assistants Primary, secondary and special schools
8	Establish an annual review process to take into account changing needs of children to teens and young adults	Primary care Social Care Mental Health teams Children, parent caregivers, kinship caregivers

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What can we learn from these narratives?

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How can services respond more appropriately?

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Are the needs of significant others taken into account?

# Acknowledgements

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This booklet would not have been possible without the immense courage of parent or kinship caregivers who never lose sight of something better for their brain injured children.

We are grateful for the collaboration with Maria Catterick from the Foetal Alcohol Spectrum Disorder (FASD) network, who works tirelessly to provide wise counsel, advocacy and information.

We hope these narratives can provide inspiration to support children to achieve their goals and bring peace of mind to parents, families and the wider community.

## Further information available from

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### Kinship carers

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