ADHD 360
MORE THAN YOUR DIAGNOSIS

360 Treatment Tools & Tips
An ADHD 360 3T's paper

From A to C: My ADHD Rollercoaster

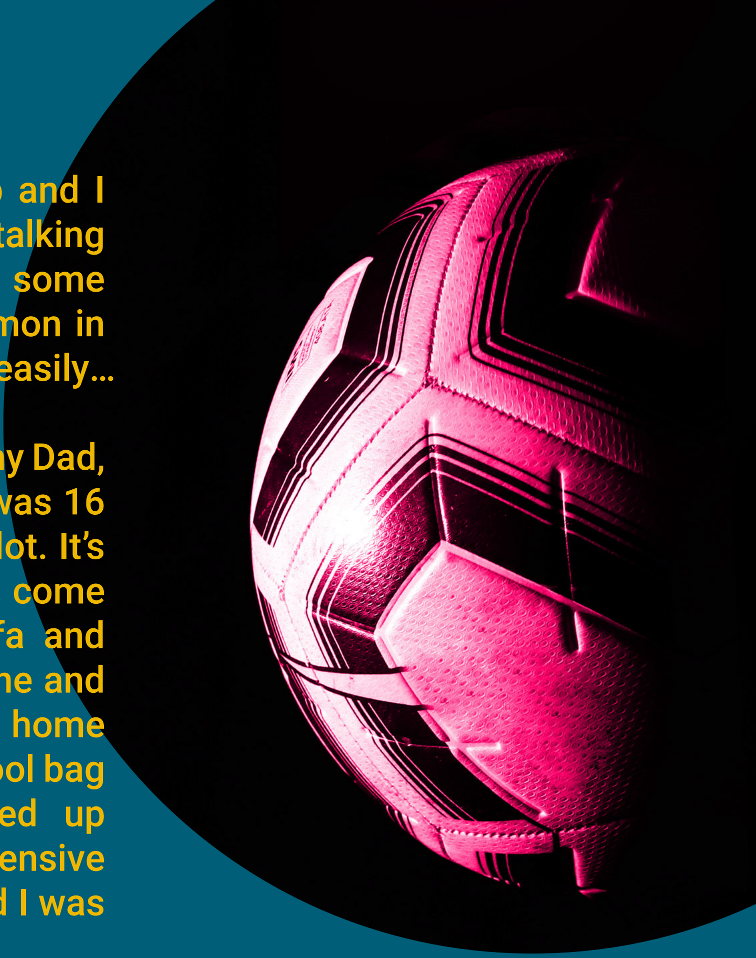
My name is Bryan, and ADHD 360, 360 for short have asked me to write down what they call my 'journey' from assessment through to today as I prepare to sit my A Levels. I have checked with 360 and I am going to start my story, as I prefer to call it, from before then.

I've agreed to do this, because my story is the same as many peoples, and I hope that by reading this, people can be encouraged. Was I fearful at the start? For sure. Was I nervous about medication, yes, and my Mum, wow she was off the scale. Would she or I change anything now, not at all. My diagnosis was one of the best things that has happened to me.

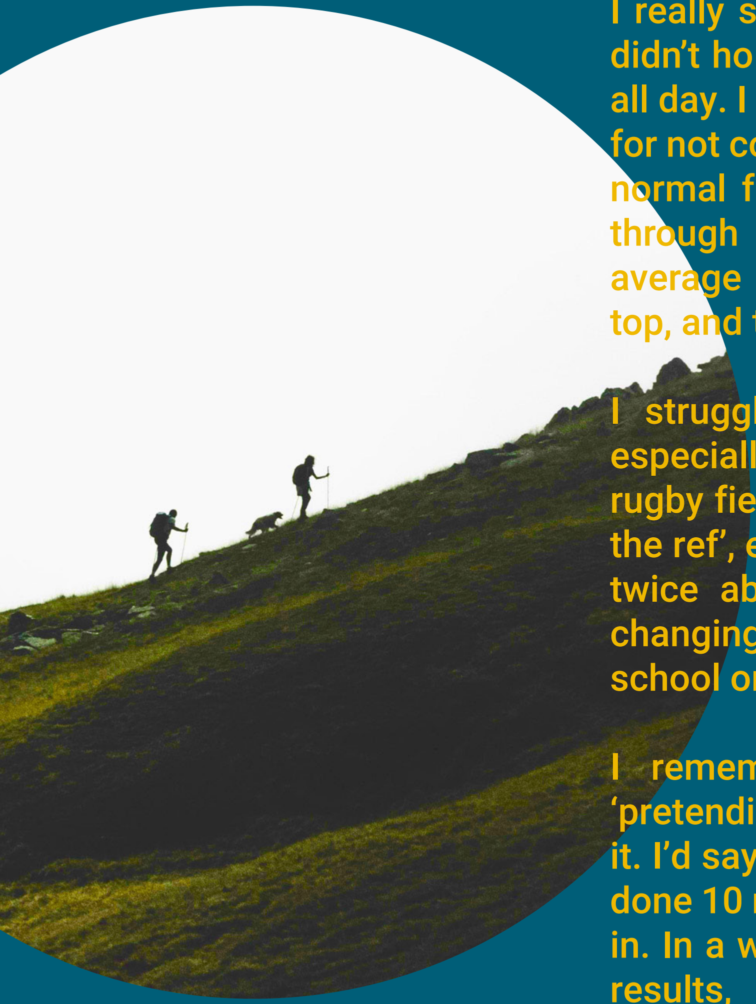
I know from my Mum that I was born 4 weeks premature, whether that has made a difference to the later development of the relevant part of my brain, the front bit, who knows. Some science, I am told by my clinician, Lisa, says there may be a connection between ADHD and premature birth, I don't know.

Fast forward to me as a youngster, I remember clearly being referred to as 'Rocket Roberts' as I used to run about ALL the time, like, everywhere, constantly. My older sister used to go to a running club, and I would go as well and the guys there would keep me entertained running, and running, and keeping up with the older group. Little did I know but I was showing my need for exercise, my incredible energy levels and perhaps for the first time in my recollection, my hyperactivity.

As a boy I needed a light on to fall to sleep and I couldn't rest with silence, so I had either talking books, or now the radio, on to provide some background noise. I've read that this is common in people with ADHD. I also don't fall asleep too easily…



I play football, rugby, cricket, I walk a lot with my Dad, and I am active, this has dropped off since I was 16 or so, but I still benefit from exercise quite a lot. It's funny because when I was about 13 I used to come home from school and collapse on the sofa and watch mindless TV, whilst playing on the phone and snapchatting my friends. Mum would come home and have to manage her frustration at my school bag dropped on the floor, my blazer scrunched up hanging off a chair and me flopped in my expensive school trousers and shirt. I look back now and I was burned out; school was exhausting.



I really struggled to follow the lessons, the teachers didn't hold my attention and my mind was wondering all day. I had to work really hard to not get into trouble for not concentrating, but I couldn't. I thought this was normal for everyone! I know now it wasn't. I did OK through school, my Mum still says today I was an average performer, not in the bottom third, not in the top, and therefore just left alone to 'get on with it'.

I struggled with confidence through these times, especially through my GCSE years. It's funny, on the rugby field I could lead the game, discuss things with the ref', even challenge the ref' at times, and not think twice about it. But I wouldn't get changed in the changing rooms and rarely mixed with a group from school or sport.

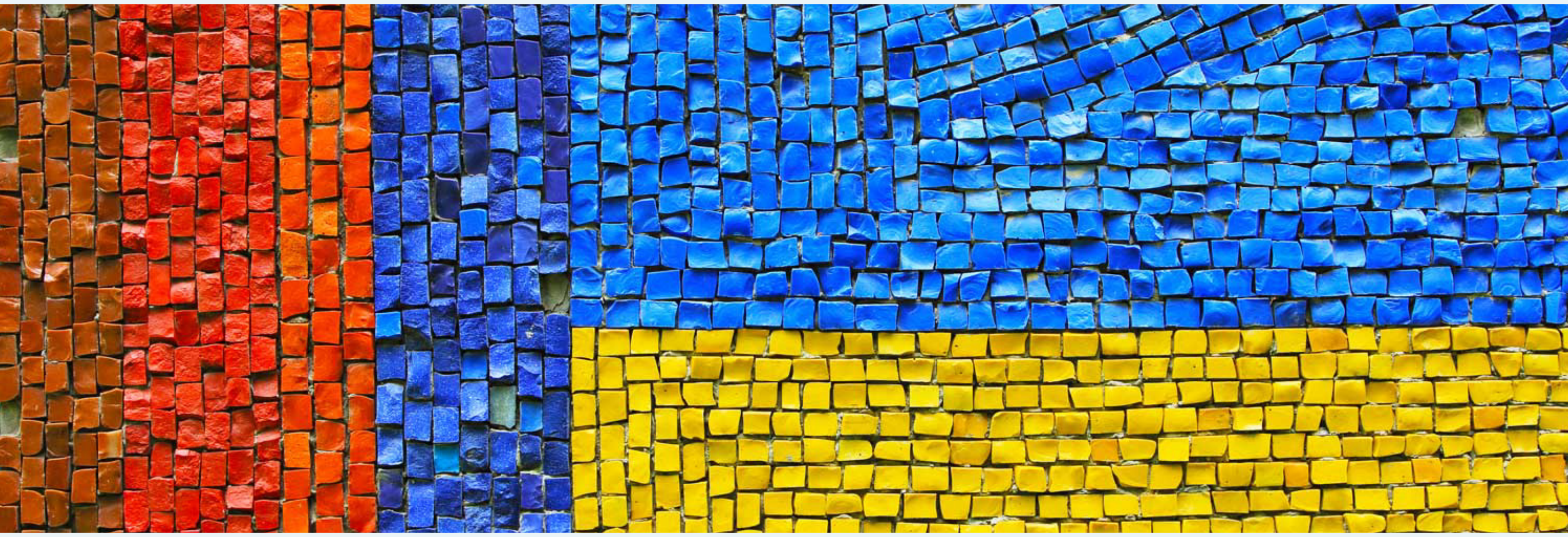
I remember sitting at home trying, Mum says 'pretending', to revise for my GCSEs. I just couldn't do it. I'd say I have done 2 hours revision, but really I had done 10 minutes in those 2 hours and that hadn't sunk in. In a way I 'blagged' my GCSEs, I got good enough results, but I know now that I didn't achieve my potential at all. Nowhere near.

I was a lucky one; my grades were good enough to get me into 6th form. But it made me sweat, it really did. And as I look back, I was convinced that I was not going to even try to go to University, no way. Whether it was my confidence, self belief or just my grades, I was 100% sure it wasn't for me. I wasn't even sure about A Levels. There was so much doubt in my mind.

Roll life on to me changing schools for my A levels and something happened, and I need to explain this in detail. For me, it is quite emotional.

I was listening to someone describe themselves and their thoughts about having this thing called ADHD. It was one of those 'chance' conversations that just happened, it wasn't planned and was totally random.

The person describing themselves said they were *"an A grade conversationalist, but a C grade student"*. That was me! I knew I lacked confidence, and my self-esteem was low but in the right circumstances I could really hold my own in a good, detailed conversation, especially if I led the conversation. I had so many examples, I could discuss things in great depth, passionately, but could I write that down as an essay? Not a chance. This person was 'talking about me'. I was amazed.



So I sat down with Mum and described this, and how I felt. I had looked up a little about ADHD, and I knew it, I just knew it.

And before I knew it, in not more than a week or so, I was sat in a clinic discussing this with Lisa, my 'amazing' clinician. I owe her so much. She has read my notes that Mum and I had sent in, I think they are now done online, and she was just brilliant at calming me down and making me feel relaxed. This was a big deal and I need lots of reassurance. Of course, I was diagnosed with ADHD, and straight away I felt a HUGE sense of relief. I didn't know what example would work best, so I asked around, and it is as if for the first time I can now see all the pieces of my life's jigsaw, and I can actually see how they relate to the picture on the lid of the jigsaw box. For 17 years I had the pieces all jumbled up with no idea of how they fitted together and how the end result would look. It is no wonder I had little self-belief and confidence, I didn't understand myself.

And that is my story really. Well that's part 1. Part 2, which I have been encouraged to tell as well, is about my treatment, my medication and where I am now.

It's been quite the ride, in truth a rollercoaster, at times thrilling, at times worrying but always under control. As I write this piece and look back at the excessive tongue rolling, the anger and aggression and the moods, I can see how easy it could have been to change this path and 'bail out' along the way. I am really glad I didn't, and that with the support of my Mum, family and of course, Lisa Mangle, I have gone from the lad with no thoughts of higher education to the UCAS applicant with high hopes of a University course! All because I heard someone say they were an A grade conversationalist and a C grade in exams. Wow! A game changer for sure.

My Treatment Path

My Mum kept a bit of a diary initially when I started on my medication and I've used her notes to capture what I need here. It's quite emotional to be fair, to follow her thoughts and emotions. I just hope me opening up, with Mum's help, can give other people the confidence to try treatment.

I took my first medicine, Elvanse 30mgs on 5th October. Wow, I had never been drunk, but is this what it felt like? I took it at 8.30 and felt 'tiddley' and then by midday, I was focused and a 'little wired'. And oh boy, did I have a dry mouth. Weird. Mum says I was loving and caring, she says she saw the best bits of me that afternoon. By teatime, I was 'done in', exhausted and crashed out. I was emotional, I could have cried, and I had a headache. I did eat tea and then went to bed. If I am honest, the end of the day, perhaps after my medicine had worn off, was horrible.

Next day, a different day, completely. No headache, no excessive dry mouth and Mum wrote down that I was using my initiative, I was calm, clear and focused and confident. I had no appetite at all for lunch, which has become a theme, but I did manage the evening meal. It was Sunday, who wouldn't want a roast? I was still 'buzzing' at 10.00pm and got to sleep very late.

Monday was my first day in school. It was a strange day, I didn't feel that the medicine helped, but I could discuss this with Mum when I got home. I didn't flop on the sofa, I was engaged and she said 'articulate' and that my awareness of things showed her my meds were actually working.

Tuesday went well. Mum says I was using my initiative more than she could remember, and that I was much happier and settled in myself. You know, the kind of words that only Mum's can use!

Wednesday was a long school day, I think there was an event at school. Mum's notes are quite funny: *"Long school day 9-9 ... Bryan arrived home exhausted, but physically hyper (twisting clothing, throwing things in the air to catch) not wanting food. He wonders if meds are still working? I believe so!"*

Thursday, I commented to Mum that I was noticing when I wasn't concentrating and when I was, and I was tired. I wasn't at all hungry all day.

Friday, movie night at home. Forget it, my meds had clearly worn off and I couldn't sit still or focus on a film. I think I annoyed everyone else by fidgeting and getting up and down. The old me?

Saturday, I went up to 50mgs, I think 360 call this titration. I had my first driving lesson today. I could and did concentrate but I was exhausted afterwards. I rested a lot in the afternoon, then as Mum put it 'rallied round at 7.00' for an hour then flopped. I nearly wrote 'crashed' but as I had been driving I have changed that to flopped.

Sunday, I had a long essay to write today and somehow managed it. I couldn't have done before treatment. I thought at the time that '50' was good for me. Mum's notes are really interesting for today: *"...in Bryan's approach to taking a shower, cleaning teeth, general appearance, being tidy, and initiative to help all have been positive steps forward. Handwriting clearer, he spoke to his grandparents about the ability to focus for longer to do his homework".*

Monday was interesting, I was sad all day. I couldn’t put my finger on it but I was agitated and ready to argue with anyone about anything. It was an unusual feeling, but Mum’s notes discuss how well I expressed this and asked to be left alone so we didn’t argue. In Mum’s notes it also talks about me becoming opinionated and holding onto my opinions come what may. This ‘forcefulness’ is unusual for me. Mum also noted that I wasn’t eating much.

This continued as a theme through the week, my week of ‘50’ as I call it. I was agitated, irritable and the focus I had previously was gone.

Saturday, three weeks into treatment now. I moved up to 70mgs today. I started with some weird facial things, I was stroking my face a lot, clicking and rolling my tongue. My tongue felt so strange, almost swollen, but it wasn’t, well not that I could see! Mum wrote that she didn’t like my facial expressions.

Sunday, I took a lot of time to ‘get going’. Mum noted that late in the afternoon I was talking non-stop and reflective, even discussing my lack of confidence about University. Mum noted the tongue rolling was extreme and making her uncomfortable, and that by 7.00 I crashed (flopped).

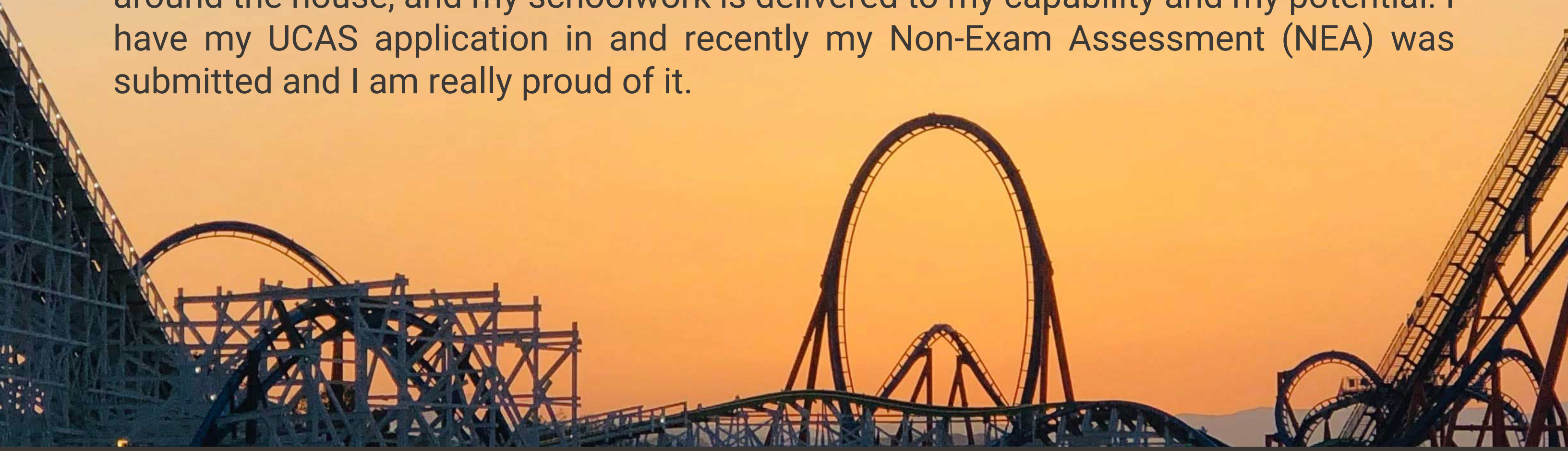
Not soon after this I decided to speak with Lisa, my clinician. I wasn’t overly happy about things, and I wanted to know what we needed to change to improve things. Her words: *“It’s early days, let's give it a while longer, as we can see improvement...”* She was right. But we did decide to ‘top up’ my medicine with an immediate release version if I had a lot of evening homework or a driving lesson.

By mid-November I was with Lisa again and we discussed my short temper and how snappy I was. My concentration was much better, my schoolwork had improved and school was ‘easier’ but I was aggressive.

By December it was clear that although my schoolwork had improved and my focus was better, I was becoming very opinionated and aggressive, especially as I 'came down' from my medicine, Elvanse. The aggression was causing issues at home and possibly with friends and we decided to change to another medicine to see what we could achieve. Mum was incredibly supportive but maybe Elvanse just wasn't for me, we had pulled back to 50mgs, which stopped all the tongue business, but the aggression was pronounced. Lisa was clear that the goal was to have a good balance between side effects and improvements, and that maybe this wasn't the right solution.

We decided to move away from the group of medicines that Elvanse is in, based on amphetamine, to another group based on the chemical in Ritalin. I took Concerta, and in a nutshell, I was a 'non-responder'; it did nothing for me at all. In January we added a non-stimulant, Atomoxetine but this didn't do anything either. Although the aggression faded to nothing, the focus and concentration didn't stay either. I was clearly needing whatever the amphetamine-based drugs did for me and nothing else. At least we knew.

We then tried an immediate release version of amphetamine-based medication, Amfexa. It's great, truly marvellous. My concentration is spot on, my focus is fab and the aggression doesn't occur. My bedroom is always tidy, I am motivated to help around the house, and my schoolwork is delivered to my capability and my potential. I have my UCAS application in and recently my Non-Exam Assessment (NEA) was submitted and I am really proud of it.



ADHD 360 Mobile & Desktop App

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Available on the App Store

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