

‘Just Focus!’ - AD(H)D or Living Life Without Remote Control.

Attention Deficit Hyperactivity Disorder in Adults - an Invisible Struggle.

In the United Kingdom AD(H)D affects about [3-5%](#) of children and [2%](#) of adults. That means in a class of 20 to 35 kids, chances are at least one of them has AD(H)D. Can you think of 50 adult relatives, friends, colleagues or acquaintances? Chances are, at least one of them will have AD(H)D, too. Chances also are, they do not know they have it. Experts estimate that three quarters of all adults with AD(H)D are undiagnosed. They might struggle in life, not knowing they could seek help and effective treatment. In fact, people with AD(H)D are over seven times [more likely to attempt suicide](#) and ten times more likely to complete it.

But what does it mean for adults to have AD(H)D? Let us imagine a few hypothetical but probable scenarios.

Picture the following situation:

Your employee and co-worker Brian has stayed at the office overnight for three days in a row. He hardly ate anything and is not seen by anyone unless they enter his office. In fact, he does not even change his posture. He seems to be so deep into his new project that even the deafening noise of the building site leaves him undisturbed. If spoken to, he barely reacts nor remembers any conversation attempt there might have been. When on the fourth day he stands at your door with a spacey look and bloodshot eyes, the project, which was scheduled to be completed in two months, is finished...

Brian has Attention Deficit Hyperactivity Disorder (AD(H)D).

You would not have thought so? No wonder, the term of this disability is heavily misleading. Individuals with AD(H)D do not lack attention, they struggle in regulating it. Hans Biegert, school director of a very successful private school in Germany that has a special teaching approach for pupils with AD(hH)D, explains it like this:

“AD(H)D is, in its essence, a self-regulatory disorder. It is not concentration but impulse and attention regulation that are disrupted.”

“I messed it all up” - AD(H)D at the workplace

You, as Brian’s boss, might feel quite ambivalent towards him: He has periods of extreme productivity and he helps the company advance with his flow of ideas and creativity. But he also rushes into the office ten minutes late every day, he procrastinates projects dangerously long and is unable to prioritise tasks. He forgets deadlines and makes careless mistakes in many projects. At one point, the survival of the company was at stake because he had sent an email containing a corporate secret to the wrong recipient. Should you fire him?

Decreased activity of the dopaminergic reward system in individuals with ADHD translates “into problems in engaging in activities that are not inherently rewarding or reinforcing.” say [studies](#). “Positive feedback can help sustaining attention,” says Biegert, who uses this knowledge to help children at his school. *That is why children with AD(H)D can focus on their Gameboy, PlayStation and Nintendo for hours on end – they constantly generate feedback.”*

Neurological differences create obstacles for people with AD(H)D not only in their personal life, but also in their professional life, as they rarely get accommodations in the workplace.

Person C, who has inattentive ADHD as well, has had “a hundred” jobs, ranging from hotel management to building theatre sets to having a takeaway business, being a runner, production manager, art director, manager, accountant executive, insurance sales agent or hypnotherapist. *“In the beginning” he says, “I was the blue-eyed boy and then things fell apart as I made a mistake or had forgotten something. Emotional dysregulation and underperformance were also an issue at work.”* After his diagnosis, person C says, *“I got into a short depression because I was mourning all the lost opportunities in my life. I had job opportunities that other people could only dream about, but I messed it all up”.*

“I started to compensate for my ADHD by working additional hours,” says person F. “Consequently, I did not have any time or energy left to try strategies that help my ADHD,

like sports. There was a time when I worked twelve to thirteen hours a day. With more and more hours in the office, I would manage to do less and less so that I would stay even longer."

Individuals with [AD\(H\)D also have a distorted perception of time](#), or time blindness, that leads to difficulties in time estimation. They also have [slower processing speed](#): the speed in which a person can understand and react to the information they receive.

Person A says *"I push myself to an impossible level to get everything done and compensate for the ADHDness in me. I compensate for my lateness by being very good at everything else."* Person B says *"I honestly think that things take less time than they do. I have been late every day but every day I believe that I would be at my destination by the time I am, in fact, leaving my house. It's depressing."*

There are not many accommodations for someone with AD(H)D in the workplace. "Autism is quite popular in a way" Cardiff researcher Syed points out, "there are accommodations for it and people understand the issues to a certain degree. AD(H)D, however, is like the poor cousin of autism." "People go like oh you have autism, so we have to adjust lots of things for you" says person A, "AD(H)D, however, is seen as a behaviour problem. But it is a [neurological difference](#). Our brains work in a different way."

Person A says it would be great if she could let someone live though ADHD for one day. "I would say 'try and live a normal day. Go to work, drop the kids off, make dinner, try to do all of those things – all with my brain. ENJOY!' I think people could not believe it. They would say 'No that's not possible.' I think people would be absolutely exhausted and not get a lot of things done. Most people would find it unbearable. They would be begging for their brains back."

"Megafocus" - a surprising phenomenon

However, among all those struggles there is one phenomenon that can help people with attention regulation problems and that occurs especially in those with more severe symptoms. It is colloquially termed as 'hyperfocus'. Hyperfocus means to be so intensely

focused on something, that one is no longer aware of the outer world or even personal physical needs. This can lead to heightened productiveness, but it can also lead to neglecting crucial tasks, appointments or meetings. Hyperfocus has been the subject of research, despite it not being listed among the diagnostic criteria for AD(H)D.

“People will always say ‘how can you know so much about this?’ and I reply: because I have just spent four days thinking about nothing else!” says person A. “ADHD means that when I am remotely interested in something I become obsessive about it.”

“I get megafocus.” says person G. “I can get more focused on things than anyone. During my law degree hyperfocus helped me to get the result that I did.”

Unfortunately, people with AD(H)D do not naturally have control over their hyperfocus, as they do not have control over their attention in general. That is why someone with AD(H)D might start a project overly enthusiastically (“hyperfocused”) but lose interest in it quite soon. Person A says: *“I can focus on things if I enjoy them but if something is not engaging it is so hard, it is almost physically painful. And it is some sort of internal thing that I cannot choose, that I don’t have any control over. I know it cannot feel like that to neurotypical people because no one would do anything!”*

“It always seems to others that you are being negligent, you are being rude.”

AD(H)D does not only lead to troubles at work, but also to problems in social relationships. This is usually sobering for both parties involved, as one feels unappreciated and neglected and the other gets increasingly desperate with their unsuccessful attempts to change their behaviour.

“Compatibility of relationships is the biggest problem for me” says person G who says his breakup with his wife was mainly due to his ADHD symptoms.” “It always seems to others that you are being negligent, you are being rude.”

“Someone will say something, and you are distracted and not give the attention that they crave and they interpret it as not being interested enough.” Says person C.

Many people with AD(H)D have [Rejection Sensitive Dysphoria](#) (RSD). It is an extreme emotional pain caused by the belief that you have disappointed others in your life and they consequently withdrew their love or respect. *“People were probably hurt because I just had no self-esteem and I dropped them because I didn’t see I was adding any value or they could possibly feel hurt”* says person C, who is affected by this feeling.

RSD does not come as a surprise if you consider that those with ADHD receive [20,000 more negative messages by age 12 than those without the condition](#). They view themselves as fundamentally different and flawed.

“Oh, I also get distracted sometimes”

If this was not hard enough, one must not forget about the stigma. A recent [study](#) concluded that the overwhelming majority of adults with AD(H)D had doubts about the validity of AD(H)D as a mental disorder. They perceived public stigma and discrimination, which caused them to suffer more psychological distress, self-esteem issues, functional impairment and decreased quality of life. In general, it made their ‘burden of disease’ much heavier.

“When I first took the medication it was like a reset.” says person A. *The inside of my head was so much quieter, I could focus and even be in time. Then my mother and I went to a parent evening and all the teachers said ‘what has changed? Your daughter is a different girl, we knew she had the potential and finally she is applying herself’ and I said ‘that’s because I’m on drugs.’ And I told them it was because I’ve got ADHD and I was medicated and they would say ‘No, not ADHD surely’. They could see this massive change but they still could not believe it. It was so frustrating.”*

“The attitude towards AD(H)D is still not very good and a lot of stigma is attached to it in the media.” says researcher Syed. People with AD(H)D often get to hear phrases like “Oh, I also get distracted sometimes” or “Yeah, I’m like that, always forgetting things...”, which can feel quite belittling for someone who is seriously affected by these dispositions.

“All of us have some of it to some degree but for someone with AD(H)D it is like that ALL the time, 24/7. It causes disruptions in their everyday life, from impeding them to focus, to hindering them to manage their relationships and their money.” says Syed. That is the difference.

AD(H)D is clearly underdiagnosed, especially in girls and women

Now, imagine our final example:

You are Lucy, a 12-year-old girl. You are daydreaming in classes and missing nearly everything. Somehow though, you manage to keep up and do well in school.

Eight years later, you find yourself at university. Suddenly, you are required to organise yourself. No one checks the homework, gives you feedback or does the laundry for you. Your room gets messy, no matter how hard you try to prevent it. You are too ashamed to allow people to visit. Often you are so late for lectures, that you decide not to go at all. If you manage to, you cannot ignore all the noise around you. Your brain shuts down.

You forget appointments. You work several nights in a row before every deadline, given you realised there was a deadline. Your grades drop. You know you are far away from reaching up to your potential. One day, you cannot stand up from bed anymore. And the next day. And the next. After two weeks you go to the doctor, asking to get diagnosed for depression.

“Adults with AD(H)D seldomly come to see a doctor or psychiatrist because of their core symptoms, but they come for disorders like substance abuse, depression or anxiety disorders, that derived from the AD(H)D in the first place” says Professor Lesch. “That is shutting the stable door after the horse has already bolted.” In fact, the discovery that many patients on the substance abuse station actually had AD(H)D as the primary condition, led Professor Lesch to research on the disorder.

“When I was studying law, I used Speed to do my assignments” says person G. “I self-medicated with drugs and drinking to try to achieve, to do things. It was not to lose my head or escape, it helped me to slow down and focus.”

Person B, who had been a drug addict as well and was diagnosed when she was 50, says: *“When I went to uni I just could not go to the library and could not understand why. And I was beating myself up all the time and could not understand why I could not get anything done. And I just kept repeating years and failing. It was a nightmare.”*

“AD(H)D is clearly underdiagnosed, especially in girls and women,” says Lesch. They often internalise symptoms and are good at fitting into the social expectations. Moreover, they tend to not show hyperactive symptoms (they have ADD instead of ADHD). There would be at least twice as many patients with AD(H)D if everyone were diagnosed, he says. *“The view of ADHD is predominantly male and negative”* says Trudy. *“I did not get diagnosed when I needed it, because I was, according to my GP ‘too academic, too bright and not disruptive enough.”*

“I have known something is not quite right for a long time” says person J. *I had seven years of counselling and clinical supervision. I thought nothing seems to (bloody) work, why can’t I just be normal? Why do I find all those things so difficult? Then I discovered it was ADHD and now I feel more normal than I have ever felt in my whole life.”*

The main problem in adults, Lesch says, is that they never reach their potential and there is a huge discrepancy between what they could and expect themselves to achieve and what they are actually achieving.

Person B, who struggles to work or do anything without the presence of another person, says *“Me, and the task, on my own, doesn’t work. I was always considered a bright underachiever. When I am alone the tasks just feel vast and huge, I want to do it but somehow, I can’t even start. I feel stuck, trapped. Every day is like a failure.”*

Diagnosis: one to [five](#) years waiting times

Person F, who was diagnosed with AD(H)D in Germany before she came to the UK says *“I was told that I had been diagnosed five years ago and managed to keep my job so it could not be that bad. It was 10 months until I got the diagnosis confirmed. When I was diagnosed in Germany, they told me the waiting time was ‘pretty long’ – around three months.”*

"I thought I might have autism," says person C, "After a year and a half I got tested for it and they said I had no autism but recommended to get tested for ADHD. That took another year and a half."

"I do not even remember," says person B. "It took ages, a couple years, they kept forgetting me."

After the diagnosis, patients often feel left alone and they do not have the money and support to access the help that they need. *"I pay 50 pounds per month for the medication while waiting for the shared plan" says person H. "I need it. When I took it I experienced what a 'focused mind' is for the first time in my life!"*

"I would prefer therapy to pills" says person B "but I just can't afford it."

"Therapy is the best thing I've done" says person A "and I know it is a privilege."

Now imagine someone with AD(H)D, diagnosed or undiagnosed, like Lucy in our example, under Corona conditions.

"Corona was very hard." Says person B. "My nice little world disappeared. I had to reinvent myself and then I realised I could not organise myself at all. All the routines broke away. And then the ADHD consultant never replied when I contacted him saying I was struggling."

At first, it might not seem straightforward that people with AD(H)D should suffer disproportionately more from the COVID-19 pandemic than neurotypicals. One [study](#) conducted in China, however, comes to the result that "during the COVID-19 outbreak, children's ADHD behaviours significantly worsened" They ascribe it to the "loss of daily routine and the lack of interpersonal and social interaction." Given that ADHD runs in families it is very likely that AD(H)D parents have to cope with that.

However, for some people with AD(H)D who continued to have some structure, Corona was a surprisingly positive experience.

"I loved Corona" says person A. I feel like all I've ever wanted is the world to stop for a bit so that I could catch up. I always feel so overwhelmed and busy and filled up in my head that all I've ever wanted is just for everything to stop." [Person A]

It's not all bad

So, what did we learn from fictional Brian and Lucy and the people who told us about their AD(H)D?

AD(H)D is a highly heritable attention regulation impediment that can be a quite debilitating factor in people's lives. Most of the time, it remains unseen. It rarely occurs alone but together with other disorders and there is a lot of stigma attached to it.

Is it all bad though? No, only people do not know that!

"The understanding and empathy for AD(H)D in the population is very limited, but so is the knowledge regarding the positive resources of it: creativity, the ability to think "outside the box" and enthusiasm" says Professor Lesch.

"I am very enthusiastic" says person G. "ADHD has helped me to create TV programmes. I have original ideas. To create anything new, that did not exist before, you have to think like that."

"If I ask you to name me 10 successful entrepreneurs" says Biegert "the majority of those probably have AD(H)D. They overcome boundaries and create new opportunities. They have the courage to try things others would shy away from."

"It is important not to disqualify it as a weakness of character" says Lesch.

For the future, researcher Syed wishes for more support for people with AD(H)D:

"For adults it is especially stigmatising to go to the psychiatrist and seek help. If there was more support, people would be more likely to seek help."

In the end, managing AD(H)D is a shared task between the individuals affected by it and society. As person J explains it to her son: *"It is not your fault that you've got ADHD and it is not the other-people-around-you's fault that you've got ADHD. You cannot allow your symptoms to impact on other people. You have to figure out how to manage them yourself, so they impact less on you and less on other people."*

"I hope that there will be a day when I can just tell someone I have ADHD and not feel like I have to convince them or explain it or argue it with them." says person E.

And person J suggests: *"Is it not about us managing it a bit and then them understanding us a bit so there is some type of middle ground?"*