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Thriving differently

How I navigate life
with autism and ADHD

HOUTEKIET

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INTRODUCTION |

Functioning in our society isn't easy when you are different. Being different is usually seen as something negative or limiting and is often even punished; you get bullied, you can't find a job, you're told that you'll never be able to do anything... And yet different kinds of brains are necessary for progress. For example, Temple Grandin once said, "Without autism traits we might still be living in caves."¹ Temple Grandin is an American zoologist and was one of the first people with autism to openly share her experiences.

I always felt I was different, but could never put my finger on it. What seemed to come naturally to others was usually so difficult for me. Why am I exhausted after a half-hour conversation? Why does it take me three times as long to read a text? Why does the new supermarket layout make me so angry? Why do I break out in a sweat when I have to talk on the phone? Why do I never belong?

These questions weren't answered until I was 27; I realized I had autism and ADHD. By then, I had obtained two master's degrees, was working full time and living independently. All my life, I have sought my own ways to function and achieve my goals. But it wasn't until I got my diagnoses that I really realized how truly difficult this was for me and why I was doing things differently from everyone else.

I also realized that I was far from the only one who had to survive with an 'abnormal' brain in our 'normal' society, so I started sharing my tips and experiences on my blog

(www.mysig.be for Dutch posts, elisecondaro.substack.com for English posts) and social media.

In this book, I'm sharing everything I know. All the tricks, coping mechanisms and insights I have developed so far. This is not a classic handbook, but a unique approach rooted in my own experience. It's intended as a form of support and an inspiration to develop your own tricks. Only you know what works for you. Find your own way, because thriving differently is possible too.

INVISIBLE DIAGNOSES

CHAPTER 1

FROM EARLY SYMPTOMS TO LATE DIAGNOSIS

A SLOW AND DREAMY CHILD

It wasn't until I was 26 that I was diagnosed with ADHD (Attention Deficit Hyperactivity Disorder) and a year later with ASD (autism spectrum disorder). My diagnoses were very difficult to trace, though clear symptoms were already present from childhood.

As a baby, I slept particularly badly. Well, at least during the hours I was expected to sleep. Actually, I kept a reverse rhythm. During the day I slept like a rose and at night I started crying, much to my parents' despair. I couldn't walk until I was eighteen months old, and I also didn't learn how to ride a bike and swim until much later than my peers. Even now, as an adult, I still feel somewhat insecure on a bicycle. Both autism and ADHD can lead to sleep problems, and difficulties with large motor skills are common in children with autism, but no one made the connection.

As a young child, I was distinctly different. I disliked things that children normally enjoy. For example, I was afraid when people played with balloons, because they could burst unexpectedly and the pop would hurt my ears. I also didn't like face painting. I couldn't tolerate anyone touching my face and the paint would itch terribly. Furthermore, I was really afraid of water and washing my hair was always a disaster.

The feeling of water running over my head, and even more horrifyingly, occasionally getting into my eyes, always triggered a panic reaction.

Once, when I went to kindergarten, Mom asked me what I did during playtime. “Spinning around a pole,” I said. Surprised as she was, she decided to sneak a peek during lunch break and sure enough, I was spinning around a concrete pillar the whole time, stroking it with one hand. I still remember exactly how that column felt, cold and smooth with bumps here and there. Spinning had a similar effect on me as playing on the swings, something I could keep doing for hours. It felt good and it calmed me down.

I could watch the same Disney movie every day for months on end. I knew my favorite movies and the stories my parents read to me word for word (even though I couldn’t read yet), and I could fully lose myself in fantasy stories. Fictional characters became my friends.

Something that characterized me very strongly as a child, and which my parents and teachers were never able to explain, let alone resolve, was my extreme inertia in ... well, everything. I was constantly distracted and very dreamy. For example, I remember how one morning I stood in line to enter class as a toddler. I stood at the very back and was so lost in thought while looking around that when I looked in front of me again, I noticed that my entire class had disappeared.

This extreme distractibility was especially problematic from primary school onward. Getting a test fully completed within the allotted time or completing other assignments

during class was almost impossible. But especially doing homework and studying for a test or exam at home were hellish endeavors. My ability to concentrate was so incredibly poor that I would sit at my desk staring at the same page for hours without making any progress. At the same time, though, I was also very conscientious and a perfectionist. So I just stayed seated until I finished, even if it took me a full weekend. Because of this, I did get good grades, and my dreaminess and slowness were never considered something to worry about. Everyone else just saw the results.

YOUTH AND STUDENT YEARS: THE FIRST QUESTION MARKS

As a teenager, I began to feel more lonely. I felt an ever-growing emptiness, but absolutely couldn't place that feeling. I also began to notice more and more that I was always the outsider. I couldn't manage to become part of a circle of friends, no matter how hard I tried and I didn't understand why. But I did begin to realize that it was because of me.

When I was nineteen, my parents divorced and that feeling of emptiness peaked. I didn't feel good about myself. Rationally I suspected there was a connection to the divorce, but emotionally I couldn't make that connection. Sometimes I even thought that I was completely apathetic about the divorce, but I did in fact have all kinds of feelings – I just couldn't name them. Was I scared, angry, disappointed...? Moreover, I didn't know how to deal with the situation or how to behave towards my parents. Now I see that the divorce brought about a major change in my life, over which

I had no control, which challenged my sense of security. The home I had always known was suddenly no longer there.

It was during this period that it first dawned on me that something was wrong and that there was more to it than just a character trait, because I wasn't dealing with my parents' divorce in a normal way. The more I thought about it, the more I was struck by all kinds of strange things.

Around the age of 20, for example, I began to develop a huge interest in David Bowie that went far beyond listening to his music. I could list all his albums in chronological order, including the release date and a whole bunch of facts. I wanted to know all the details to the point of absurdity. It felt safe to collect and memorize facts. Somehow it gave me something to hold on to. It was also a form of escapism for me. Around age 12, I developed a pervasive interest in the world of Harry Potter, and a number of other themes similarly bewitched me at the time. My interests helped me, but sometimes they became compulsive in nature and a source of stress when I noticed that something was missing or not right. People with autism often encounter that, but I myself found it hard to place. Nevertheless, I developed a way to deal with that stress. Whenever my interest threatened to become an obsession and cause me more stress than pleasure, I would force myself to take a time-out. I forced myself to do absolutely nothing related to that interest for an sustained period of time, and with success. These breaks were gratifying, and afterwards I was able to deal with my interests in a healthy way again.

Furthermore, I also became more aware of my rigidity, my need for control and the tremendous stress that came with it. When I went to study in Siberia for a semester during the final year of my master's, I thought it would do me good to leave everything behind for a while, get away from all the environmental factors that might have made me who I was, so I could find my way back to my authentic core. Well, that didn't exactly turn out the way I had expected. I absolutely could not find my bearings there. I slept much worse than at home, was always very tired, felt lethargic and then – for the first time – I got asked, “Are you autistic?” The other students seemed to adapt so easily and immediately made Russian friends. I didn't understand why I couldn't, and the feeling of emptiness, loneliness and loss of control that had been present for years ballooned.

A SEVEN-YEAR QUEST

After my parents' divorce, aged nineteen, I started digging. I wanted to know what was wrong with me, but most of all I wanted to find solutions so I could start feeling better. I had no idea where to start, so I turned to doctor Google and started reading a lot.

I also went to several agencies for help, but was always told that there was nothing wrong with me and that I just needed to relax a little. This was very frustrating because I felt that my symptoms were not taken seriously. Now I realize that I never gave caregivers all the pieces of the puzzle. I simply didn't know that a lot of my personal characteristics were symptoms, so I didn't mention them. Moreover, I had a very hard time describing my emotions.

After years of searching, I finally figured out my diagnoses on my own. Part of the reason it took so long was because of the image I had of autism and ADHD. The only thing I knew about these disorders was what I had seen and heard about in the media, which mostly pertained to extreme cases in children.

When I was in the final year of my master's, I overheard a classmate talking about ADHD and ADD. I asked him what the differences were and he told me that ADD consists mainly of concentration problems. I had never considered that the enormous concentration problems that I had suffered so much from all my life could possibly be a symptom, so the moment he said that, I knew I was onto something. I immediately ran to my dorm room and started surfing the web at the speed of light, looking for information about AD(H)D. Finally, after years of searching, I cried "Eureka!" Everything made sense, I couldn't believe it. But when I shared my findings with a psychologist I had been seeing for several weeks at the time, her response was irritating: "You can't have ADHD, because you have several degrees. There is nothing wrong with you at all."

This comment made me feel like I was acting out and I ended up waiting another six months before I went to a psychiatrist with the specific question of whether I had ADHD. I was looking for a job at the time and knew that working would be pretty difficult because of my attention problems, so I definitely wanted clarity. After several months, I finally got the redeeming verdict. I did in fact have ADHD. At the time, I was 26 years old.

Soon I realized that ADHD didn't cover the full scope of what I struggled with and that there had to be something else. This suspicion became stronger when I got another

position at work where I had to coordinate marketing campaigns and be in charge of contacting clients. I knew beforehand that I would have a hard time doing that, but I believed I would grow and get better at it. Unfortunately, that didn't happen and after a few slip-ups I had to return to my previous position. This was the first time in my life that my otherness had really led to problems. I continued my search.

At that time I had a boyfriend with autism and in order to understand him better, I looked up all kinds of things about this disorder. I remember standing in a bookstore flipping through the book *Brein bedriegt* by Peter Vermeulen (highly recommended, by the way) and I couldn't believe what I was reading. It was as if a complete stranger had written my autobiography.

My psychiatrist thought this was a remarkable discovery. She herself had never thought of autism and recommended that I go to a diagnostic center. This is how I ended up at Triangel (a multidisciplinary diagnostic and therapy center) where they listened to my story attentively. They took me through the diagnostic process and it clearly showed that I had autism.

At least on paper. Because I could hide it tremendously well. The psychologist who gave me the final verdict could hardly believe how well I was functioning and how 'normal' I appeared. He said he had been doing his job for ten years and usually picked up signs of autism at the intake interview. But with me he didn't notice anything, even now that he was aware I had it.

I soon discovered that everything I had achieved in my life up to that point was actually quite remarkable. For example, my research revealed that I scored particularly low on

one part of the IQ test. I have a working memory of only 77 IQ points. Just to outline, that's worse than 99 percent of the rest of my age group. The fact that I had studied with such a wretched working memory was amazing, the psychologist thought. "That must have been quite a struggle," he said. He hit the nail on the head.

LATE DIAGNOSIS BY CAMOUFLAGE

I am not an isolated case. A lot of individuals with autism and/or ADHD and normal to high intelligence manage to camouflage their symptoms extremely well (often also called 'masking') and develop all sorts of coping mechanisms to function.

By camouflaging, I mean masking my 'weirdness'. In other words, I pretend to be normal, such as in social situations, where I'll ask people questions I have thought of beforehand in order to have a seemingly smooth conversation or adjust my body language to appear socially desirable. Camouflaging, then, is the difference between how a person comes across and what is actually going on inside that person's head.

Examples of what I call compensating or applying coping mechanisms are things like taking a nap before a social event or figuring out tricks to function at work despite my concentration problems.

Camouflaging and compensating are techniques that are often developed unconsciously and arise from a natural

desire to fit into society. So those who become very good at masking their autism and/or ADHD often remain undiagnosed for much longer.

WOMEN

Women in particular remain under the radar for a long time. Most women with autism are not diagnosed until adulthood and often on their own initiative. Numbers wise, we're talking 25 percent compared to 7 percent of men.²

One reason is that women are very good at camouflaging. Most women with autism and/or ADHD are keenly aware of their otherness and social shortcomings and are always looking for ways to hide it. To fit in, they start to observe and copy the behavior of people who are popular. Women in our society also face more pressure to behave in socially desirable ways, feeling they need to fit in.³

A second important reason is that the diagnostic criteria are based on the symptoms in men, so a huge number of women are missed. It used to be thought that both autism and ADHD occurred almost exclusively in men, but this turns out not to be true. Moreover, a lot of medical professionals are also not completely up-to-date, so they don't recognize the symptoms in women. Very recently, one of Britain's leading neuroscientists, Professor Francesca Happé, sounded the alarm. The stress that comes with camouflaging and lack of proper diagnosis - and thus appropriate help - often lead women to suffering from other mental health problems, such as depression, anxiety disorders, burnout, self-harm, and eating disorders.⁴

CONSEQUENCES OF A LATE DIAGNOSIS

LONELY BATTLE

Going through life without any diagnoses was pretty tough. I was often not understood and could not fall back on the right help such as practical or psychological support, tutoring, and medication. Especially at school, better support, or even a few adjustments, could have made a big difference to how much I would have suffered. I always had to fight my battles alone.

Even now, after my diagnoses, it remains a lonely battle as I continue to camouflage. That I appear to function normally and have been living independently doesn't mean that my autism and ADHD have disappeared. On the surface, I may seem perfectly fine, but inside I still experience the same problems. You can compare my autism and ADHD to an iceberg. Only 10 percent of them are reflected in my behavior. The other 90 percent I experience alone and is invisible to others. As a result, people often have too high expectations of me and don't take my difficulties into account. Maybe it's up to me to more upfront about this, but I don't like to be the one ruining the fun. Moreover, it's difficult for others to imagine what it's like and to really understand me. For example, when I do muster up the courage to indicate that a certain day or situation will be difficult for me, I'm often told afterwards that "it wasn't so bad after all", simply because I didn't show my unease. Or "you survived", as if the fact that something is transitory makes up for everything and I shouldn't have whined. I'm sure it's all well-meant, but