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Words

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I collect words like a friend of mine collects Facebook and Twitter and Instagram followers: I have lists and lists of them on my computer, mind-map after mind-map of them in my notebooks. I take pleasure in their tastes and textures; the initial presence of a word in my mouth, how it rebounds through my body, moves in and out of me. I love how ‘linguistic’, ‘semantic’, and ‘semiotic’ roll off my tongue, shimmy through my shoulders and gyrate at my hips, round and round. There’s a special kind of sexiness, I think, reserved for ‘pedantic’.

Some evenings I obsessively scroll through my spreadsheets or flick through my notebooks, admiring my word collection—as I imagine my friend does her statistics across her social media. ‘You do it for enjoyment and validation,’ my therapist had surmised when I confessed to such a compulsion, ‘but also, I imagine, for a sense of ownership, a sense of control.’

I had ended up as an outpatient of a crisis team, again. I had been referred to them after breaking down at the doctor’s. There I had sobbed, retched, and recoiled at my intrusive thoughts on numbers, time, and death. I remember saying that I wanted to kill myself on my birthday because I liked the symmetry. A couple of months after that and I was apparently suitable for discharge from the team. I’d arrived at the final assessment with a psychologist, having spent the previous weeks reformulating my diagnoses with countless others.

This psychologist was explaining that I needed to build up my portfolio of mental health conditions. It would be like having a whole other CV: ‘So, there’s the bipolar that runs through the middle, up and down like a wave on a graph. Underneath that, there are all of your comorbid anxieties. And even further below those, there's your death anxiety, a foundation of sorts. Your underlying death anxiety makes you try to control the things you can't by trying to control the things you think you can, producing your obsessive-compulsive disorder as well as your sensory processing disorder (though I appreciate that's formally undiagnosed). Your comorbid anxieties exacerbate your mood disorder, which, in turn, heightens your OCD and SPD.'

There he had it. Bipolar, comorbid anxieties, death anxiety, OCD, SPD. Messy, multiplicitous words. I was aiming for something neater, more compact: a single answer, one word. I was searching for a grand unified theory of my mental health. A theory of—a word for—everything. An elegant and exhaustive and increasingly unlikely solution. The psychologist was sitting there, smugly, as if he had completed a particularly challenging cryptic crossword without checking the cheats. I knew he was as distracted as all the others. While they assessed, classified, taxonimised, diagnosed, they were always looking the other way to whatever it was I was trying to articulate, which would recede and then withdraw out of sight, under words upon words upon words, remaining un-deciphered code.

Some words, like 'calculate', 'enumerate', 'formulate', I drool over. Others I cannot stomach. Numbers affect me the most severely, both positively and negatively. A few months before the breakdown at the doctor's—and the subsequent referral to the crisis team—I was advised to have assessments for autism spectrum condition (ASC). I moved back to my parents' house from university and completed my postgraduate degree from there.

The word 'autism' was promising. I thought it might contain the answer; finally, a something for everything. The assessment results came through the post. The letter read, 'You have a dislike for even numbers. You love your birth date as it is all odd numbers. Odd and even numbers are associated with colours. For example, odd numbers are yellow, black, and red. Even numbers are pink and green.' The association of words (or numbers) with colours is known as grapheme-colour synaesthesia, one of the most common types. I picked my GCSE and A-Level subjects, as well as my undergrad and postgrad modules, based on how I saw them as colours. My interest in the topics themselves was irrelevant. The letter continued: 'You described panicking about shapes, colours, objects, and textures, and there are many things you find sensorially offensive.' Like the poor grammar in this letter, I fumed as I read it, which I couldn't not correct.

‘They don’t think I have Asperger’s,’ I said, sitting down with my parents. I had gone to my room to read the letter on my own.

‘Why not?’ said mum, eyebrows raised. We were all surprised.

‘They said I demonstrate many characteristics of high-functioning autism, but not all of them. There’s a suggestion that it might be more “sensory processing disorder” (amongst other things), but there would have to be more tests and more waiting lists for that to be confirmed.’

‘Are there any suggestions as to where to go from here?’ mum asked. She should have known better.

‘No,’ I replied, looking down at the letter. ‘Not really.’

‘So that’s it,’ she concluded, trying to contain her anger, presumably for my sake. ‘No more help offered. Thank god you didn’t spend all your savings on those private assessments.’

I nodded. Then I had to go back inside because she had cleared her throat in the way that made me want to strangle her. Dad hadn’t said anything throughout. We were all disappointed.

The autism assessments had left me deeply embarrassed. Not for the first time, I felt accused of making it all up—like I had been looking for attention, as several of my friends thought. One of them had told me, in no uncertain terms, that ‘those who chase diagnoses get diagnoses.’ I waited until after I was discharged from the crisis team—all those months after the autism assessment results—to contact them. I wrote, ‘It’s not about me “chasing” a diagnosis or wanting to add another string to my bow. Unfortunately, I operate in a system which will not help me unless I am diagnosed with something. It is not about whether you or I think I have Asperger’s, it is about listening to your friend, understanding their concerns and offering your opinion if they ask for it.’ We made up after that.

‘Sorry I was overly-sensitive,’ I said later, on the phone.

‘Sorry I wasn’t sensitive enough,’ was the reply.

I had been applying for a PhD in Film Studies and had written a proposal on cinema and autism. I’d met with potential supervisors and funding for the three years would have been in place. After I had the assessment results back, however, it was as though I had lost any potential authority on the topic. I no longer thought I had a claim to ‘autism’: I felt that I would have been appropriating and exploiting the condition. All of the words I had been reading and writing and collecting for that project slowly faded into the distance and out of legitimate use.

I was deeply embarrassed because I *had* been chasing a diagnosis; I *had* wanted to add another string to my bow. I thought that one word—'autism'—might contain the answer in a way that two or three or the twenty or so words I ended up with simply wouldn't.

I knew all along that a diagnosis is inherently arbitrary. That it is just one word or, perhaps, several. It doesn't prove, nor disprove, lived reality, not really. For me though, 'autism' was a claim to legitimacy, a much-needed key to unlocking help, an explanation for family and friends. Even if I had been diagnosed with 'autism', I doubt it would have changed my identity, treatment, or relationships. Most likely, I'd have come to the same conclusion via different workings: the realisation that psychiatric language is random, vague, and often misleading—on both sides of the diagnostic line. The conditions systematised in the DSM-5 are made from a number of letters just like all the other words: signs and signifiers, nothing more.

My one-word hypothesis had fallen through. Soon after I worked out one word wouldn't do, I knew that neither would two nor three nor twenty. I needed hundreds, thousands, hundreds of thousands. I needed all the words in my spreadsheets and notebooks and more. I needed to reclaim the language of my mental health, away from the psychiatric and towards the personal. It didn't have to be one or the other, I'd already decided that, so much as a combination of the two. I'd take all my medications, check in with my therapist and the doctors when I was required to, have my blood tests on time, and fill in the never-ending questionnaires. I'd do all the things I'm supposed to do, but also, I'd write.

I needed my own words, not just those given to me. I needed words I could use to express myself with, to have fun with, to hit the target rather than miss: I needed (and I wanted) to play with language, grammar, and syntax. It wouldn't be enough to simply read and write and collect anymore; I wanted to neologise, coin, invent, create. I turned my back on academic writing (I dropped the PhD applications altogether at the end of that year) and gave creative nonfiction a go.

***Laura Grace Simpkins** is a creative nonfiction writer whose personal essays describe her mental health using colours, shapes, and patterns. Her work has been published by The Guardian, Yoga International, and The Polyphony, and has been broadcast on BBC Radio Bristol. Simpkins is currently collaborating with the Wellcome Collection on a research project about medication and the environment, and is developing her first book, Lithification. Her website is at* lauragsimpkins.com.