

The Health of Autistic Women: State of the Field and Future Directions – Patient Perspective



Alcohol masked my autism so well, that nobody noticed it until I got sober

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Abstract

A personal story about how alcohol can be an effective but problematic masking tool for autistic women.

Keywords

addiction, autism, drinking, masking, social camouflage, women

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For a long time, my natural instinct on seeing a person I know, unexpectedly, was to hide. Interactions with acquaintances were awkward, confusing and stressful. Did we know each other well enough to stop and talk or was it acceptable to smile, wave and keep going? And, if I did not manage to hide in time, and *god forbid*, found myself in an impromptu social interaction, what was it *appropriate* to talk about?

I have finally worked out that you are not supposed to answer the ubiquitous question of 'How are you?' honestly.

'I'm more depressed than I've ever been in my life', makes people uncomfortable. Especially when they are just trying to pick up milk in the supermarket.

Nobody *really* wants to know how you are, in spite of endlessly asking.

I still often tell people how I truly am, because I cannot help it. They ask, and so I answer. Afterwards, I remember the strange rule around 'how are you' and berate myself for failing to adhere to it, yet again.

See. Stressful.

Give me a beer, however, and I would no longer feel the need to hide. I became talkative and confident — eager, even — to chat to people I knew only vaguely. Three pints of beer and I could dazzle strangers with my quick wit and risky humour. Four pints and . . . Well, your guess is as good as mine, to be honest, since I tended to blackout around that point.

Any drinker knows that the trick with booze is to get the dose right. Something I was never very good at it. But my god! That first half an hour of drinking. When I could relax and talk, and stop being so afraid about which rules I was breaking, or how I was coming across. Alcohol was something special, and I quickly fell into a toxic love/hate with it.

People talk about booze 'taking the edge off' and it seems like this effect could be especially profound in those of us who are autistic. Kurchak² explains the bliss of booze wonderfully in her book, *I Overcame Autism and All I Got Was this Lousy Anxiety Disorder*: 'Alcohol dulls the stage parent-esque voice that is always screaming at the back of my mind, monitoring and criticizing my every breath, taunting me to do better and reminding me that I'm probably screwing things up miserably' (p.115).

Being criticized for being yourself, and pulled up on all the ways you interact 'inappropriately', across a lifetime creates an extremely critical inner voice and a deep self-consciousness about how you are perceived. As a result, interactions with people outside of your inner circle can be confusing and even distressing. When I am earnest, for example, people often read me as sarcastic. When I am sarcastic, people think I am serious. My jokes often receive awkward silence while my serious questions are met with peals of laughter. This persistent unpredictability means I

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struggle to feel comfortable in social environments. And so I learned, from a young age, to lean on alcohol.

Only to discover, in my thirties that rather than helping, as I had believed, alcohol was actually ruining the quality of my relationships, including my relationship with myself, and so I set about getting sober.

I was shocked to find I could not quit by myself as I had always believed, and after a number of failed attempts at a year of abstinence I tried Alcoholics Anonymous (AA). These peer support meetings held in churches and scout huts gradually became places I felt *almost* comfortable sober (in spite of the horribly bright lights). The clearly stated rules of engagement (no interrupting, introduce yourself by name each time you speak, say hello to the speaker by name each time they introduce themselves) and frequent repetitions offered clear guidance on how to join in and so I could manage without the support of beer.

The Twelve Steps promised to be a guide for living without alcohol, something I desperately needed, and so I began. A kind, sober woman mentored me through the process of learning to live in the world without relying on drink, and with her help I grew more comfortable and confident with my social awkwardness, tendency towards anxiety and love of being alone. I rediscovered my love of nature and animals, became a gardener and fell in love with a man who adored this quieter, more reserved iteration of me. Learning to cope without drinking was not easy. But I gradually cultivated a more compassionate inner voice and worked on accepting myself, as I actually was.

My reliance on alcohol had hidden a lot. Social anxiety, low self-esteem due to my general ineptitude at every day life, a tendency towards rumination and procrastination and difficulty regulating – or even recognizing – my (many) emotions.

Four and a half years after getting sober, I was discussing my issues with a Special Educational Needs (SEN) teacher friend, because I suspected attention deficit hyperactivity disorder (ADHD), when she asked if I had ever considered autism. She told me how autistic girls and women, especially, can avoid diagnosis due to their proficiency at masking their difficulties,3 often by mimicking their peers. The material she sent me to read on this subject was transformational, as significant as finally identifying that I had a drinking problem, and the self-acceptance work begun in AA took on a new dimension. I stopped pushing myself so hard to 'keep up' with my peers and 'act normal' in social situations, and my mood variability began to settle down as I learned to plan for and manage my limited energy more effectively. I stopped feeling so ashamed of my intense sensitivities and 'over-the-top' reactions, and built more rest and quiet time into my life on a daily basis.

Now I am 40 years, with a diagnosis of autism and ADHD and 7 years of sobriety. This might not sound like a

traditional happy ending, but it is. Sobriety has given me a peace, clarity and self-acceptance that I had not previously experienced, and diagnoses have brought self-compassion, forgiveness and healing.⁴ My relationships are strong and healthy today, and I have an incredible support network, because I finally know I need help and am capable of asking for (and offering) it.

Since I understand myself better, I do not hide from people the way I used to. I have come to understand why small talk exists. Not simply to torture me, and keep us trapped forever in fake and superficial interactions, but as a form of kindness, something that helps other people feel more comfortable. When you are very lucky, it can even create a gateway to true connection. Who knew?

Armed with self-knowledge, I am working on making a life in which I do not need to mask so much. I am able to make more informed choices about who I spend time with, where I go and what I do, as well as seeking support to help me do the things I find challenging. I am beginning to get help from local charities and research projects, as well as from Access to Work and other schemes I am eligible for.

Today my life is quieter, richer and vastly more organized. I still struggle to keep up with everything sometimes, but in the same way that most people do. I no longer feel chronically behind my peers the way I did when I drank to cope. I am growing to love the gentle, nurturing and naïve person that I am. I remember her from childhood. She was too soft for the world she found herself in then, and alcohol helped her to build a tougher shell to survive. These days I know better ways to take care of her. I surround myself with understanding and compassionate people, and I remind myself it is okay to make mistakes. Which is important, because I really do make an extraordinary amount of them. Progress has not been easy or linear, but my quest to feel better, which began almost 7 years ago with quitting drinking, and led to my dual diagnosis a couple of years ago, has been worth it.

Last year, my partner and I bought a house with a garden, and this spring we are having a baby, something I never fully dreamed of, because I did not think I could manage it. I am excited about the future in a way that I never used to be when I was undiagnosed and dependent on beer to survive. Some days, managing my life still feels like a gigantic challenge, but as I continue to make choices that require less masking, and asking for help, it keeps getting easier.

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Consent for publication

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