

## On Writing While Disabled

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So, as Miss Ross once put it, I'm coming out. Not as a big old bender - that's old news like Gorbachev. I'm coming out as a disabled person.

But wait. If you're disabled isn't obvious? No. Not necessarily to anyone else. And not necessarily to yourself. Of course, there's the perennial question of denial: 'I can't be disabled because...', and that is often reinforced by the dominant images we have in our society of disabled people using wheelchairs and/or having severe learning difficulties that are obvious to even a casual observer. And I don't use a chair (yet), and my learning difficulties are not apparent to most people at first glance - I have three degrees (sadly though with no solo by Sheila Ferguson), learned a foreign language well enough to teach it at MA level, and was a full Professor by the age of 33. Not bad for a no-mark lower middle-class kid from the arse end of North Wales. But I can't read graphs or maps properly, have very little visual or spatial awareness because of poor proprioception, and when I can't understand something, I **really** don't get it. I struggle to define my feelings (Brianson Enterprises: Putting the Alex into Alexithymia since 1969), and often experience life as a baffling and exhausting puzzle.

But in my case it hasn't been denial, really, unless I'm also in denial about that, but rather about the time it takes for something I grasp intellectually to filter down into my heart, or wherever it is our emotions reside, and then back up again to my brain in a way it can recognise.

Because I'm disabled.

In fact, if we use the law of England and Wales as the definition, I'm disabled in four different ways: long-term and deep depression, long-term general anxiety disorder, Chronic Fatigue Syndrome/ME, and autism. It's impossible for me to know how these all intersect because the symptoms can be identical, and I haven't always been playing with the full diagnostic pack, so I can't just do a little archaeology and compare. I was diagnosed with CFS in 1998, depression in 1993 (although I'd had it before), Asperger's Syndrome in 2018, and anxiety at the same time, because until my autism diagnosis, I didn't know what I felt was anxiety - I thought everyone felt this way all the time. Depression and anxiety are often associated with, and considered symptoms of, autism, and may be related to the way autistic people's brains function and/or to the way we usually experience social isolation. And clearly I have always been autistic, I just didn't know it; had I been born a couple of decades later it might have been identified while I was at school, but then's the breaks.

So why now? The short answer is that at 51 I am finally accepting that this is going to be my life, because the various therapies and medications I've been on for the last 6 years haven't made much difference to anything but my self-understanding, which is of course precious and worthwhile but no practical use to me unless I employ it to change my life. This has become utterly pellucid recently, during the period in which I've been mourning my mum. My fatigue has been crushing because this is how my particular Aspie brain processes grief - somatisation, which I learnt recently means the physical manifestation of psychological/emotional symptoms. In this period it has become very clear to me that if biology is not destiny it nonetheless sends you off down a given road and puts huge barriers

in the way of lane-changing. A period of grief is not how life always is, of course, but just like addicts often have to reach rock bottom before they can start recovery, I have had to reach this extreme circumstance to see my normality as being forever on the same spectrum as other disabled people, but just at a different point from those in some of the stereotypes.

The longer answer to the 'Why now?' question is more complicated. Buckle up, reader dear.

First, there are reasons about my own quality of life. There's no use setting myself up to fail by giving myself unrealistic goals. 'Oh, you can be anything you want to be,' say lifestyle coaches and people trying to be nice. But actually, no you can't. I could, if my body let me, play a lot more tennis and gain more skills, but I am never going to win Roland Garros. Similarly, I can write when energy permits (it hasn't for the last year), but I'm never going to be a novelist if by that I mean a third career. Realising that has been liberating, and a huge release of self-imposed pressure to succeed.

And there's power in claiming the 'D' word as part of my identity – legitimisation of myself in my own eyes as someone who genuinely and understandably can do less than most people, and thus I no longer have to beat myself up about it. Calling myself disabled also gives me recognition from others, and even from the state: I have a group I can belong to, and benefits to claim, because that's who I am now. A concrete example is all the help, pointers, opportunities to help others, and recognition of myself in others' dilemmas I've experienced through autistic Twitter, which has been a damn sight more than I got from the NHS or even the charity sector: provision for adult-diagnosis autistics is lamentable in the UK.

Using the 'D' word about myself also helps me make my health my top priority. So often I have hated myself for not being able to do more on a given day, especially as the dream of being a professional writer slipped further into the future or an alternative reality. The guilt I felt about doing progressively less regarding the care of my mum, albeit having ramped it back up again in her last months at great cost to myself, has been crippling. No pun intended. Actual, physical pain and so many tears were my world because I felt useless and wrong. That lifted when mum died, but left echoes I'm working through now, and owning the 'D' word is helping.

Similarly, recognising my disability may in time remove or even lessen the grief I feel at the loss of my plans, capacities, and prospects entailed by my conditions. There are ways in which this strikes to my very core: I grew up in a family beset by financial problems, and worked my arse off to ensure I could escape that, so finding myself on benefits and having to reduce my savings ever more has been not just scary but deeply angering, because, as many a teenager has noted, it *just isn't fair*. But it is reality, and I am grateful for the fact I had economically fat years before everything collapsed; my situation is not the same as that of someone who has never been able to work, and in that respect I have privilege that I acknowledge.

That said, having a Past That Was Different has also been problematic psychologically, because the most invidiously hobbling comparisons I make are not between myself and others (I learnt that was a terrible thing years ago, and although it crops up in times of emotional crisis such as now, in general it's not a huge difficulty for me any longer), but those between Alex 2021 and Alex 2006-12, when I was at my professional and volunteering/social change group peaks. And I have to admit that past Alex was a damn sight

more useful and accomplished than present Alex. I *am* diminished, and there's no point soft-soaping it. Really recognising my disability helps me come to terms with that, and to hope there may be other ways in which I have realistic prospects of being useful to others even now.

As a well-executed segue, claiming my disability in all its nuances, restrictions, and differences may help me challenge stereotypes in ways I used to do about being gay. In the eighties and early nineties I lost count of the times people said things like, 'Of course, if they were all like you, Alex, it wouldn't be a problem,' and that gave me an opening for a spot of prejudice challenging. If I ever get more of a public profile as a writer, I might be able to do something like that for autistic people. The research establishment says we have no theory of mind (AKA empathy), you see, which presumably makes being an Oscar-winning actor like Sir Anthony Hopkins a bit difficult, and yet somehow it happens 😊. Bad science can become holy writ in a way I can understand from my academic career, so I may be well-placed for that.

Finally – and yes, love, you've been patient, thank you – how does this Great Big Disability Pride Thing affect my writing, given that's supposed to be the focus of this 'ere blog? So far, I think there are two main ways, but I may discover more. After my diagnosis I read pretty widely on Asperger's, but so much of it went in one ear and out the other because of disability and overload, and I'm going back to it now.

The first impact on my writing is in what I can conjure up from my own lifeworld in my fiction, following the Divine Jane's injunction to write about what you know. (Don't @ me with objections to, limitations of, and opposing views to, said writing advice; it comes from the best and so I officially Do Not Care.) In novel 1, the still-unpublished *Sympathetic Magic*, this is reflected in the creation and use of a dual-narrator structure, with both voices being of a being who is wrapped up in the material world but not quite of it at the same time. In novel 2, the similarly deprived of great public acclaim *Excessively Diverted*, it's behind the creation of one of the key characters, Nick Bennet, and drives not only his central dilemma but also his approach to life in a way that's key to the plot rather than incidental or woven-in-for-edginess.

The second way my disability affects my writing, it turns out, is in my style and relationship with language. Like many Aspies, I often use cultural reference points as a means of conveying ideas or experiences; in real life this is a useful means of finding a simplification of something that seems very complex otherwise. In *Sympathetic Magic*, Scandi-pop and Eurovision are not just the basis for chapter titles that sum up the action of the following pages, but also a reflection of my lifeworld and huge splashes of local colour, given that the action takes place in the Holy Land (for new readers, this of course means Sweden.) In *Excessively Diverted*, Nick's love for Kylie (I wonder how that crossed my mind 😊) is not just a feature of his life, but a fairly good example of an Aspie special interest (AKA 'obsession'), given the fact that at his age – mid-twenties – Our Lady is not as natural a diva of choice as Gaga or Dua Lipa or Arianna Grande, and her music and career shapes how he communicates about his life. I did something very sweet with that related to his boyfriend, and if the book ever sees the light of day, you can read it for yourself.

So there you have it. World, I'm disabled. And that, dear reader, is that.

