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Disinhibited Thoughts #3

Tourette's Syndrome is a disorder full of irony, paradox, and non-intuition. "The tick you hate the most is the one you do the most". "The only way to lose a tick is to not notice that you've lost it, or else it will be back". Because of these and other aspects of TS, when I was younger I thought my disorder was aimed at me personally. This TS thing in my head was alive, seeking out the things that embarrassed and angered me most, so that it might prey on them and make me as miserable as humanly possible. Educating myself in the neurology and psychology of TS has allowed me to better understand its principles. Does that make the TS go away? No. But it helps me to understand why I should expect certain things to happen, without attributing those things to evil intent, or poor character. And that DOES help – I am no longer a strange, bad person, or a hopeless victim of some malevolent demon. I am a proactive problem-solver, with the good intentions and know-how to anticipate, avoid, and modify the situations that will logically cause my disorder to worsen. In a sense, by understanding TS I am distancing myself from it. Rather than being an unwilling *participant* in TS, I've become a dispassionate *observer* of it.

One familiar irony that comes to mind a lot now that I'm no longer living alone is, "The TS urges always get worse as I'm around more and more people". At one time (when I suppressed), the only time I ticked was when I was alone, because that's the only time I ALLOWED myself to. Once I stopped suppressing though, I found that I would sit at home alone for an entire night or weekend without thinking about my TS, but as soon as I went out in public it was back. This seemed such willful cruelty that the truth ended up being almost boring in comparison: TS is made worse by stimulation. Anytime stimulation increases in your head, whether it is through hunger, being tired, the stress of upcoming exams, being touched, or *simply being near another person*, you can expect your disorder(s) to worsen, whether that means increased ticks, sensory sensitivities, obsessing, or distractibility.

That's it. A simple, emotionless, objective principle. This to me is yet another irony of TS, and a tragic one at that – so often there are very plain, neurological reasons for why we do what we do, but when we don't know what those reasons are, we personalize. We put the onus of these actions on our own emotions and qualities, and beat ourselves up when there is no call for it.

I'm glad I learned that stuff about stimulation heightening TS. Otherwise when my girlfriend moved in with me, and my symptoms increased, this might have surprised me. In the absence of the real explanation, I might have concluded that my bigger ticks and more restless mood were because she made me uncomfortable. Maybe I didn't even like her. For sure I would have concluded this when I found that my skin crawled from her touch, making me pull away. And it absolutely would have been over the first time I decided that I sometimes wanted to sleep alone on the couch rather than in our bed. Our wonderful, strong relationship could have been destroyed. And still the damage could have continued. After repeated failed relationships I may even have eventually decided that it was obvious I didn't like people, and that I deserved to remain single and alone forever. All this, not *because* of my TS, or because I didn't like people, but because I didn't *understand* my TS.

I implore you all: learn about your TS, and teach what you learn to your partners, family, and friends. There are enough people out there who will misinterpret, misjudge, and misperceive what we do without doing it ourselves

Until next time, my friends!
Duncan
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