

# To Disclose or Not to Disclose your Diagnosis to Friends Story and Art By Haley Moss

In my twenty years as a person on the autism spectrum, I've learned that friendships and relationships outside of my family are one of the most fascinating concepts and one of the most complicated things out there. To begin with, humans are naturally social creatures. Since the dawn of time, pretty much, humans have found ways to communicate and cooperate with one another. However, this social component of our existence isn't exactly natural for me or anyone else on the autism spectrum, and the friends we do have are pretty special people.

I've often run into the "to disclose or not to disclose" conundrum when getting to meet people and when moving past the acquaintance level to being friends or more than friends. Feelings on whether or not someone should share a huge part of their identity vary. Some only talk about autism on a need-to-know basis while others wear it on their sleeve like a badge of honor.

With disclosing, I have figured out that people usually fall into one of three distinct camps:

- 1. Those who accept, understand and are willing to learn alongside me;
- 2. Those who accept and say nothing changed until it personally affects them; and
- 3. Those who are completely in the dark, so we go our separate ways.

Not knowing which of those three responses you will get is scary, but for me, choosing to disclose to possible friends, current friends, or partners is worth the risk. This is a personal choice, and I am not saying my choices will work for everyone. But I share with you how and why I have chosen to disclose in certain situations so that someone else out there who may be on the fence on whether or not to open up and/or how to may be helped.

### Haley = Autism

I used to only disclose to very close friends since I did not want to be judged any differently. Once upon a time, the only people who knew of my autism were my family, my best friend, and school administrators and teachers. Today, the

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people who know are all of you reading this, my family, current and former friends, anyone who asks what kind of job I have or will want outside of college, anyone who has seen me give a talk or has seen my artwork, and nearly any friend I have or will make. I am in an unusual position with this disclosure question. In a sense, I live and breathe autism. I advocate, raise awareness, fundraise, and write about it often enough. The autism and greater disability community make me feel at home. "Haley" and "autism" are synonymous the minute you do a Google search on me. If I don't say anything, people might assume I am ashamed of my autism or that I am trying to hide something.

#### **Disclosing Right Away**

Sometimes, you may feel obligated to disclose right off the bat. I often fall into this category. I believe it is a great weed-out of sorts since those who can't handle it seem to make it very clear before either party becomes emotionally invested in a friendship-to-be, and it saves a lot of time to find out earlier on rather than later at a graduation party when the noise is too much and you want to leave in order to avoid sensory overload. In that scenario, I can then kiss our friendship goodbye because someone didn't know or understand why I behaved in a certain way.

Disclosing early also opens up a lot of windows for questions. A lot of people I have met over the years at various stages in our

friendships have been afraid to ask questions. If you disclose to friends or acquaintances/soonto-be-friends/potential partners, I recommend you do it in a way that shows confidence and indicate whether or not you are open to questions. I've asked numerous times why the people who were electively in my tight social sphere, despite knowing I am autistic, did not ask questions until they absolutely had no choice (i.e., the time a friend and I left a rap concert because it was too much for me and he could not understand how/why it was overwhelming).

I tend to preface my disclosures nowadays with a footnote: "I encourage questions, except that I cannot speak for anyone but myself—as in, if your cousin or distant friend is autistic, I can't explain their behaviors." It is a healthy reminder that every person on the autism spectrum is a unique individual and that no two autistics are exactly the same.

#### Waiting to Disclose Could Cause Even More Problems

Postponing disclosure could also brew a bit of confused trouble with friends. Instead of the understanding, patient pals you may have before disclosing and explaining autism, you may be met with a bit of frustration and anger. Questions and comments such as "Why didn't you tell me?" or "You know you could trust me" could very well plague the initial important talk you could possibly share to-





## When to Disclose to a College or Employer

The decision to disclose to a possible employer or a university you want to attend is much different than disclosing to a friend. While every decision is personal, here are some tips to keep in mind:

- If you need accommodations at a college or university, you need to ask for them, which will require disclosing your diagnosis. The sooner this is set in motion (right after acceptance), the better. This means opening a dialog with the appropriate office on campus, usually called Disability Support Services (DSS). (Note: If you are asking for SAT testing accommodations, you will need to apply to the College Board for them ahead of time. Talk to your school counselor about the process.)
- Employers are forbidden by the ADA from asking about disabilities at an interview. You can disclose a disability to an employer at any time in the hiring or post-hiring process. If you need accommodations, it is wise to disclose by the time you accept an offer of employment. While you may wait until after you start a job to disclose a disability and though asking for a reasonable accommodation on the first day or later is within your rights, this will not foster a positive relationship between you and your employer.

The above tips were adapted from the Pathfinders for Autism website.

gether. These people became so focused on why you didn't tell them instead of what you did tell them or what it means now.

When in a friendship with someone on the spectrum, I think knowing helps color in the picture of why someone may behave a certain way, or maybe you won't be offended if a person with autism says something and doesn't realize you're upset. That kind of important information should be shared earlier rather than later.

#### A Personal Choice

I have found disclosing my diagnosis to potential and current friends to be a helpful, timesaving and honest practice. I have also perfected how I do it. Naturally, the way I disclose to friends may be different than how I would disclose to a partner or an employer. I tweak what and how I say to fit a situation best, if necessary.

Disclosing an autism diagnosis is a personal choice, and whatever decision you make in regard to it is yours and yours alone and should be respected.

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