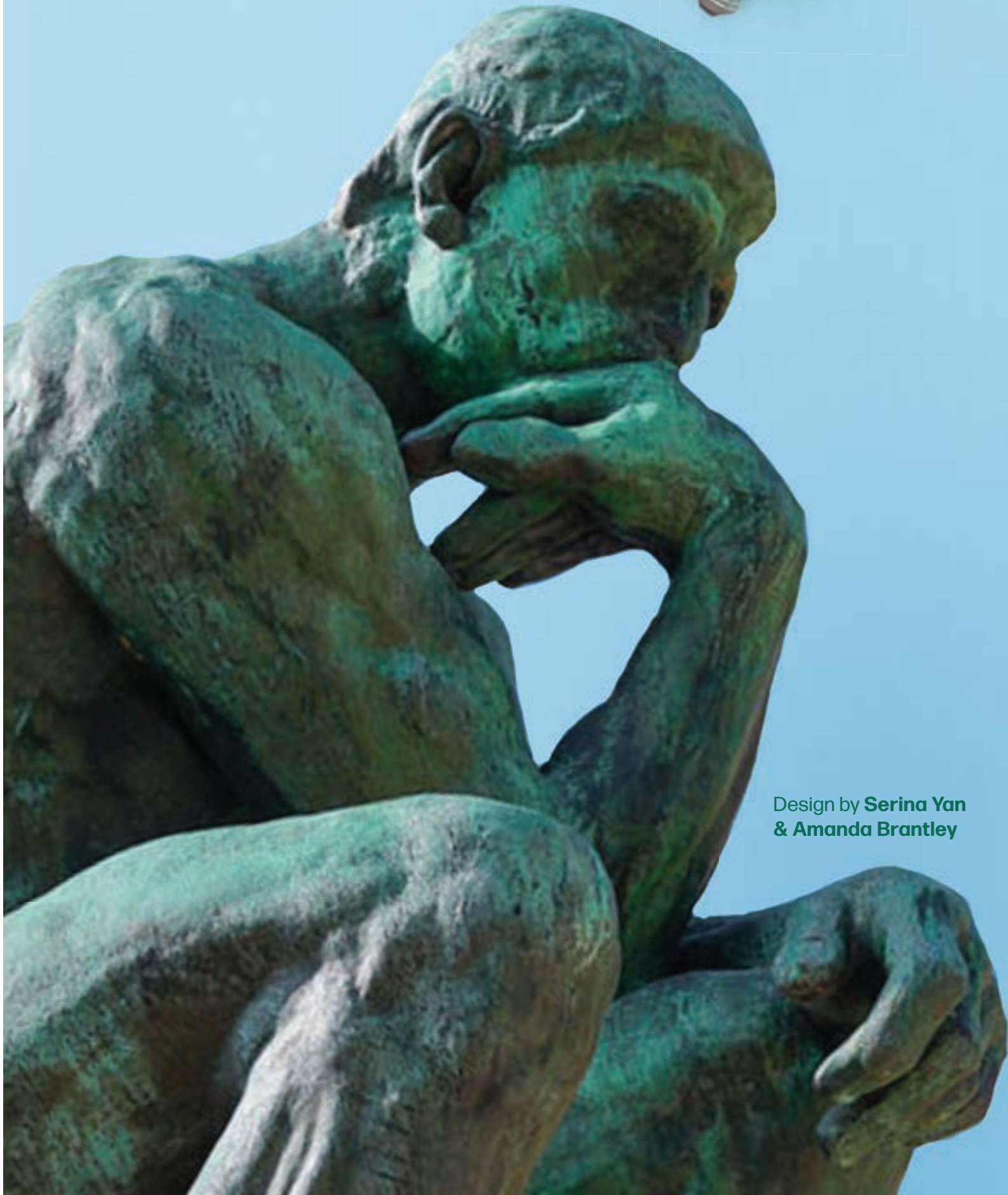


# ***THINKING DIFFERENTLY*** **ABOUT** **THINKING DIFFERENTLY**

Story by Elizabeth Hu, Annie Jones & Lucy Walker



Design by **Serina Yan**  
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# THINKING DIFFERENTLY ABOUT THINKING DIFFERENTLY

Students navigate neurodiversity on and off campus

Story by Elizabeth Hu, Annie Jones & Lucy Walker  
Design by Amanda Brantley & Serina Yan

Our goal with this article is to remind our community that neurodivergent minds may not be typical, but they are normal. The National Library of Medicine estimates that 15 to 20 percent of Americans are neurodivergent, but – in the experiences of these writers – we at St. John's tend to assume that everyone is neurotypical. The neurodivergent experience is often difficult and isolating, so we hope that sharing these stories brings some comfort to readers that can relate – and that it helps neurotypical students to better understand and accommodate their peers.

Some names have been changed to protect privacy. Sources who are referred to by only one name have asked to remain anonymous.

When Jade was seven, her mother decorated the front yard with Halloween-themed stakes, but Jade, not her real name, did not approve of the layout. After her parents put her to bed, she snuck out to rearrange them to her liking. There was no visible order to her arrangement – they were not ordered by height or organized in neat rows, but she felt that her layout was somehow more correct. Her mother made her put them back in their original places the next morning.

"I cried and cried," Jade said. "I don't know how no one caught that something was up with me."

Jade was diagnosed with autism when she was 13. Perceptions about autism, she said, are narrow and pervasive, so people who exhibit behaviors beyond the stereotypical set of symptoms are rarely recognized by their peers – or diagnosed by psychiatrists.

"I'm someone that doesn't fit the common description of an autistic person: little boy with horrible social awareness, and really, really good at math," Jade said. "And because I don't fit that, people expect me to be one of the 'normal ones.' It's like I'm some sort of ambassador."

For Jade, one of the most troublesome aspects of her autism is her fear of change. As a child, she refused to clean her room because she would miss the familiarity of the mess. When her parents threatened to throw everything out, "it was like the end of the world. Everything needed to be how I was used to it being."

After three years of therapy, Jade has gotten better at handling unfamiliarity.

For example, a year and a half ago, her parents replaced the carpet in her room with wood flooring, much to Jade's dismay. Instead of shutting down, she forced herself to look at the floors and walk around barefoot to get used to the new texture.

"That initial shock of change never really goes away. I'm always

going to have that," Jade said. "I've just changed the way that I cope."

Jade received her ADHD and autism diagnoses after her psychiatrist suggested that she be tested.

"I didn't have any concept of what that meant aside from what you see in media – and that's typically a very negative or infantilizing portrayal," Jade said.

One of the first clues that she might have autism was her sensory issues, which mean that some sounds or textures trigger a stress response, even if most people would not find those stimuli distressing. Jade never wore baggy clothes because she hated the feeling of fabric brushing against her skin. She hates loud noises, especially when they overlap from different sources – the sound of people talking can sometimes feel "sharp, like someone is shooting a dart at my head."

Jade got tested the summer before ninth grade to see if she could qualify for academic accommodations. She spent two days at a testing center where she was asked to read a picture book aloud, solve basic arithmetic problems and spell easy words.

"It was a demeaning process," she said. "I already have this feeling that something is wrong with me, and then, because I'm asked to do these things that I've been doing since I was a child, it adds onto this feeling that I am here because I am messed up, and there is something in my brain that is wrong, and I am childish and I am stupid."

## AUTISM SPEAKS, BUT FOR WHOM?

Autism Speaks is one of the world's largest autism awareness organizations. Founded in 2005 by grandparents of a child with autism, the group's website claims that they improve global awareness and inclusion, advocate for the rights of individuals with autism, and increase access to services, support and research for advancements in autism care.

Autism Speaks mostly focuses on advising parents of children with autism rather than supporting the children themselves. There is only one person with Autism Spectrum Disorder on their Board of Directors – the rest have children or relatives on the spectrum. Two are trained psychologists; 23 serve or have served in leadership roles of major corporations like AMC Networks, AutoZone and Goldman Sachs.

Their detractors point out that Autism Speaks uses their platform to create an attitude of fear and mystery around people with autism while just 1% of their operating budget actually goes toward family support, according to the Autistic Self Advocacy Network. There have also been complaints that the organization exaggerates stories and statistics. In a 2013 article written by co-founder Suzanne Wright, she compared autism to the plight of "missing" or "gravely ill"

children, which proved so controversial that a member of the organization's Science Advisory Board resigned in protest.

"Autism Speaks claims they're giving autistic people a voice," Jade said. "Autistic people have a voice – you're just not listening to them."

In a 2009 ad for Autism Speaks, a narrator personifying autism said, among other things, "If you're happily married, I will make sure that your marriage fails... You have no cure for me. Your scientists don't have the resources, and I relish their desperation... I will fight to take away your hope. I will plot to rob you of your children and your dreams. I will make sure that every day you wake up, you will cry."

Jade stresses that a parent's life is not over if their child has autism – they just have to adjust their parenting style. Loving a child and seeing them for who they are is part of being a supportive parent. "Worshipping" an organization, especially one that treats autism as a problem in need of fixing, is not.

In 2007, Autism Speaks merged with Cure Autism Now, which described itself as "an organization of parents, clinicians, and scientists dedicated to finding effective biological treatments, prevention, and a cure for autism and related disorders." The National Institutes of Health does not consider autism an "illness" and says that treatment should focus on helping people cope with symptoms rather than eliminating them.

"When you pity autistic people or are overly saccharine to autistic people, it's infantilizing. Why are autistic people being treated as pets?" Jade said. "You don't need to be solved because you're autistic, you need to be treated with respect. You need to be treated like a human being – because you are a human being."

Jade said that people usually perceive autism as "a terrible sickness that ruins the life of anyone who is afflicted with it," and that people with autism are often called brave or heroic just for being alive. But for Jade, being called an inspiration – or hearing the common catchphrase that "autism is a superpower" – feels patronizing and performative.

"I'm not a superhero. I'm not an inspiration," Jade said. "I'm just a high school student that lives my life a little bit differently than other people. Using me to make yourself look like an ally doesn't make you a good person – it makes you someone who gets off on the idea that you're a savior to people that don't need to be saved."

## 'IT'S WHO I AM'

Daphne's parents first realized that she might be neurodivergent when she drew shapes instead of numbers on a third-grade math test. Soon she was diagnosed with ADHD, dyslexia and dysgraphia on the same day. "I've got the Big Three, as you call them," she said.

But it was not until Daphne reached middle school and began receiving extended time that she felt different from

her peers. Taking assessments in a separate room felt like being "cordoned off," and she grew tired of questions about her whereabouts and why she needed accommodations.

"It was isolating, but you just have to own it," Daphne said. "There's two options: you could sit there and feel terrible about yourself and feel stupid all the time, or you can embrace it. And for me it's been the second."

Reading proves particularly challenging for Daphne, now a senior. In order to understand a text, she has to put all her focus into stringing the letters together. Audiobooks are a big help.

Daphne attended dyslexia treatment sessions three times a week throughout middle school, working extensively on reading comprehension. Therapy and years of practice have mitigated the symptoms of dysgraphia, a neurological condition in which someone has difficulty turning their thoughts into written language. She used to struggle with writing even when she was visualizing the correct letters – the distance between her thoughts and the page was difficult to traverse.

Before she got tested, Daphne's parents noticed the common symptoms of ADHD that their daughter exhibited such as excess energy and tending to be loud. But another, less visible aspect of her ADHD is her habit of procrastinating – when faced with a big assignment, Daphne often feels physically unable to get up and do it. As she entered high school, "procrastination's become a big thing that I've had to really consciously try to overcome."

Daphne has been on medication since sixth grade, and while it has improved her focus and academic performance, the physical and behavioral side effects can be extreme. Stimulants used to treat ADHD suppress hunger, which hindered her performance in lacrosse when she did not eat enough.

"It definitely has affected my relationships," she said. "I've been asked, 'Do you ever feel like you're not the true you because of the meds?' Because I've been on meds so long, I don't know."

Daphne has always been open about her neurodiversity. Sometimes people make jokes or assumptions about her intelligence, which prevents her from connecting with them. But she knows that her learning differences are nothing to hide from. "It's who I am."

## LEVELING THE PLAYING FIELD

Upper School Academic Support Coordinator Karina Soto helps neurodiverse students secure accommodations, including extended time. She follows the suggestions on a student's psychoeducational assessment, "a comprehensive report that highlights how an individual thinks and operates," which they receive after testing, school counselor Jake Davis said.

Right now, the only accommodations that St. John's can guarantee to eligible students are extended time and preferential seating. "We align with what the College Board and ACT are looking for," Soto said. "We don't change what is learned and how it is learned."

Soto said that her goal for each student she sees is to educate their parents and teachers on how best to support them. She also wants students to understand that accommodations are not unfair advantages, and that neurodiverse learners should not feel guilty for using them. Similarly, they should not feel that needing accommodations means they are less intelligent.

Daphne's classmates frequently say that she is "lucky" to have extended time – ignoring the fact that it takes her significantly longer to read and write, and that she often has to re-read questions three or four times to understand them. Both she and Jade have been told by classmates that they are "cheating" on the ACT by taking it with extended time. "Schools have traditionally been set up for a particular kind of learner," Davis said. "So for some people, when a program totally meets their needs, it might be easy to look at other people whose needs aren't being met and falsely think that accommodations are a leg up."

Davis noticed that the stigma surrounding extended time increased after the 2019 college admissions scandal, when wealthy parents paid for false diagnoses so their children could qualify for unwarranted extended time and score higher on standardized tests.

"In some cases, people have tried to abuse the system, and that has caused some to question its validity," Davis said. "But the people who get hurt the most by this rhetoric are the ones who really need the accommodations."

## RUNNING ALL THE TIME

Three days after her interview with The Review, senior Ava Mostyn ran into a tree branch in her backyard and got a black eye.

Mostyn runs into things a lot. Once, she collided with a table and bruised her hip, but she did not realize that she was injured until a friend pointed it out – and even then, she thought it was a smudge of dirt.

Mostyn, who has ADHD, lacks spatial awareness and depth perception.

"They would tell me in drivers' ed to turn on the blinker a hundred feet before the stops," Mostyn said. "I don't know where that is. Where's the ruler? I don't see it."

Mostyn decided to get tested at the end of her freshman year after realizing that she was not having the same high school experience as her friends. She would often burst into tears over an assignment while her classmates did not understand what was so difficult about it.

"I felt like I was playing chess, but no one taught me the rules," Mostyn said. "How did you get your pawn over there? I can't move mine."

Her therapist said she had ADHD, but to receive extended time, Mostyn was required to receive an official diagnosis.

Mostyn's diagnostic process took two days. One activity tested her processing by having her press a space bar when an "X" showed on a screen but refraining when other things appeared. Mostyn also had to match symbols to decode a paragraph within a certain amount of time to test her pattern recognition. What she hated the most was guessing the relationship between two images.

"They never told you if you were right. You could just say whatever you wanted, and they'd move on," Mostyn said. "At one point, I completely made things up about a door and a beach. I was like, 'Are you going to think I'm crazy?'"

People without accommodations sometimes think that if they had extended time, they would do much better. While Mostyn acknowledges that this is true, she emphasizes that "I need that [extra] time to accomplish what you can do in the time you have." She could spend half an hour outlining an in-class essay – not something the College Board recommends – so she needs that time to calm down and properly structure her essay. Mostyn also makes her teachers aware of her learning habits.

"I always put in my little course intro survey that I fidget," Mostyn said. "But that doesn't mean I'm not paying attention. That means I'm trying to pay attention."

Mostyn's ADHD also manifests itself in her organization skills. One time, when she told her therapist that her messy desk was stressing her out, her therapist accurately guessed how the desk was organized: everything in a circle with the items she uses the most on one side of the circle. Mostyn attributes this behavior to "weird brain pattern things."

Exercise is a must for Mostyn. If she doesn't work out before she goes to bed, she cannot fall asleep: "My brain needs to be physically tired since it's running so fast all the time."

While the psychological benefits of exercising also manifest in neurotypical people, her heightened symptoms due to ADHD set Mostyn apart.

## UNDERSTANDING NEURODIVERSITY

### neurodiversity

The complete spectrum of neurological differences. People with learning or developmental differences are neurodivergent; those without them are neurotypical.

### sensory issues

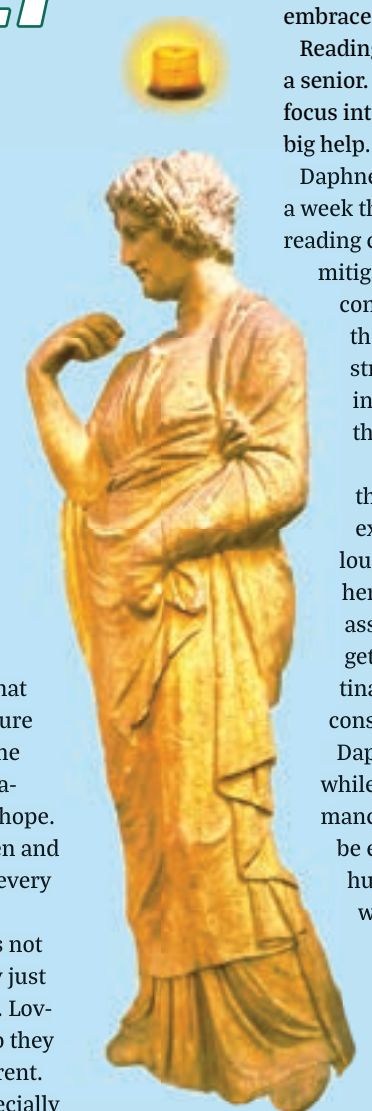
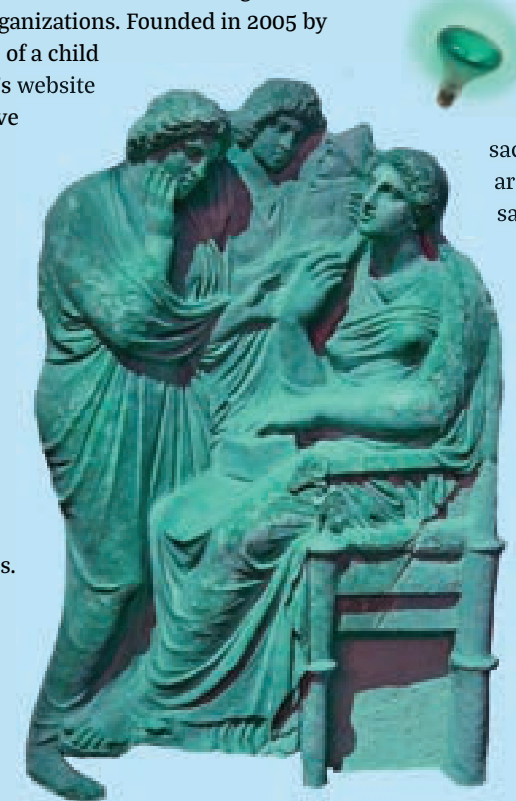
A symptom of autism and sensory processing disorder. People with sensory issues are distressed by certain stimuli, which can be anything from overlapping sounds to the texture of foods.

### exposure-response therapy

The best treatment for obsessive-compulsive disorder. People with OCD have certain triggers that cause the need to perform a compulsion, and not performing it causes anxiety. In exposure-response therapy, patients are presented with a trigger and have to avoid performing the compulsion until their anxiety subsides.

### extended time

A student who undergoes diagnostic testing will receive a psychoeducational evaluation, a comprehensive report explaining the results. If this evaluation recommends that the student receive extended time, they can meet with the Academic Support Coordinator to qualify for 150% extended time on all assessments.



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St. John's sometimes grants people extended time temporarily while they undergo the diagnostic process, but Mostyn says the school culture prevents people from talking openly about neurodiversity.

"We have a very set image of what a St. John's student looks like – what they do in their free time, how they learn, how they study," Mostyn said. "For a lot of people, they don't want to talk about having or needing accommodations because they think it will make them feel like they don't fit in."

Mostyn has discovered that her preferred study method does not involve reading and rewriting textbook passages. She likes to record herself talking about a topic and often asks her friends to watch her explain a problem.

"A lot of it is understanding the way I study," Mostyn said. "Not feeling like I have to study a certain way because it's how other people do it relieved a lot of the pressure I felt freshman year."

## OBSESSIONS & CONFESSIONS

In fifth grade, Delilah started to feel near-constant urges to confess. It did not matter if she hadn't done anything particularly bad – or anything at all – she would still feel guilty.

Since her older sister had exhibited similar symptoms at her age, her parents recognized them as signs of obsessive-compulsive disorder.

When her symptoms worsened in eighth grade, she was officially diagnosed with a type of OCD called scrupulosity and prescribed anti-anxiety medication.

Scrupulosity is a psychological disorder characterized by pathological guilt or obsession with absolution, which is often accompanied by compulsive moral or religious observance. However, Delilah is not religious. Instead of confessing to a priest, she confesses to her mother.

The guilt also manifests itself as more common OCD symptoms, including tapping on walls and a fixation on the number three. In eighth grade, she would erase all her work if she didn't write everything perfectly, resulting in short math worksheets taking several hours.

The imagined consequences for not satisfying these compulsions can be extreme.

"Once I was playing piano and I was like, 'If I don't repeat this measure five times, my dad's going to die.' Or that if I didn't tap, I wasn't going to get into college," she said. "It's an irrational thought that just pops into your brain and then you suddenly feel guilty for it."

Even if individuals with OCD recognize their intrusive thoughts as irrational, they can still feel an overwhelming fear that they will come true. Indulging these compulsions only temporarily relieves anxiety. The best treatment for OCD, exposure-response therapy, aims to combat these compulsions. Patients are exposed to anxiety-inducing situations and must try to avoid performing the associated actions.

Repeated exposure lessens that anxiety, and patients can become less dependent on their compulsions.

With exposure therapy,

Delilah's urge to engage in repetitive behaviors has waned, but the constant guilt and urge

to confess have not. This obsession has put stress on her relationship with her mother, who knows that she isn't supposed to let Delilah act on her compulsions, but she doesn't want to see her daughter in distress.

Delilah tries to avoid ticcing at school, and she rarely talks about her diagnosis. "None of my friends really know the full extent," she said.

Jokes mischaracterizing OCD – saying someone who likes lining up their pencils neatly has the disorder, for example – discourages Delilah from talking about how distressing her symptoms can be. But talking about it helps.

"I'm very lucky to be able to see a therapist and to have an incredibly supportive family."

## NAVIGATING COLLEGE APPS

The sleep schedules of most high school seniors are a mess – especially Delilah's.

In the most stressful phases of the college application process, the urge to tap on her bedroom walls was so intense that it kept her up at night. On the day her Early Decision college results were released, she kept tapping three times on the walls at school.

She decided to focus her Common Application essay on dealing with academic pressure and OCD, but writing about neurodiversity in college essays is not a simple decision. "It is a deeply personal topic," college counselor Steven Scales said, and while students sometimes have to write about their learning differences to qualify for accommodations or programs, it can do more harm than good.

"It's a case-by-case, strategic choice," Scales said. "Sometimes I do not recommend that students reveal that they have a learning difference because the college may have a different perspective. But if you're applying for a program that has excellent learning services, and that's one of the reasons you're applying, then that's relevant to show interest."

## THE VOICES IN HER HEAD

As a child, Brooklyn was bubbly, curious and made friends easily – including imaginary ones. But as she grew older, her parents began to worry about the voices in her head. The problem wasn't that the voices were dangerous or rude – but that they never went away.

Brooklyn has auditory hallucinations associated with mild schizophrenia, which means she continually hears things that are not there. She regularly hears sirens and car horns when she's driving, even when no one is honking. Her mother has found her talking to walls for several hours, having a conversation with someone who is not there.

Over the years, Brooklyn has found ways to ignore her auditory hallucinations – she frequently reminds herself that they are in her head and listens to loud music to block them out. But most people require exposure therapy or medication to overcome their hallucinations, so it is hard for Brooklyn to connect with others in her therapy group.

"My therapist was telling me, 'maybe you can teach these other people how you did it,' but I can't do that because we don't have the same experiences," Brooklyn said. "They're having dangerous voices – I have little whimsical ones."

Brooklyn's diagnostic process

took several months and cost thousands of dollars. Testing was not covered by her parents' insurance, but they were willing to pay out-of-pocket.

She describes applying for testing accommodations at SJS as difficult – she requested them for her diagnosed anxiety but was required to receive an additional diagnosis from a school-approved practitioner to qualify. She spent five hours sitting for questionnaires and completing puzzles, expecting a diagnosis of anxiety and potentially ADHD. She felt almost guilty for assuming she needed testing, and she contemplated whether her experiences really deserved a response of "frequently" or "always."

"It was incredibly difficult to go through all of the tests because they make you so mentally worn out and make you feel as if you are different from everyone else," Brooklyn said. "Should I be checking all yes or should I be checking all no? That's a question I kept asking myself, but I chose truthfully."

The resulting diagnosis surprised and scared her. "I walked away that day not with ADHD, but with schizophrenia," she said. "I was afraid people were going to think I was crazy – I was only 14. People still do think I'm crazy, but I laugh it all off."

*All photos: Creative Commons*

