



Real People, Real Stories:

# Autism Spectrum Disorder

*The*  
**MIGHTY**

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PRESENTS

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Whether you (or someone you love) have just received an autism diagnosis, have been a part of the autism community for a while, or simply want to learn more about autism, this book of stories is for you.

This book is comprised of stories from the perspective of people on the autism spectrum as well as parents and other loved ones in the community. You'll read powerful responses to questions like, "What does autism feel like?" and "Why is eye contact hard for you?" You'll learn about the importance of autistic "obsessions" and the impact eating issues can have. You'll also follow the journey of a wife and her husband after realizing he, like their daughter, is on the autism spectrum. You'll find these stories and more in the following pages.

All of these stories have appeared on The Mighty, a site where people share their personal experiences with disability, disease and mental illness. Visit our [submissions page](#) to learn about sharing a story with us — we'd love to read yours.

Stay Mighty,

The Mighty Team

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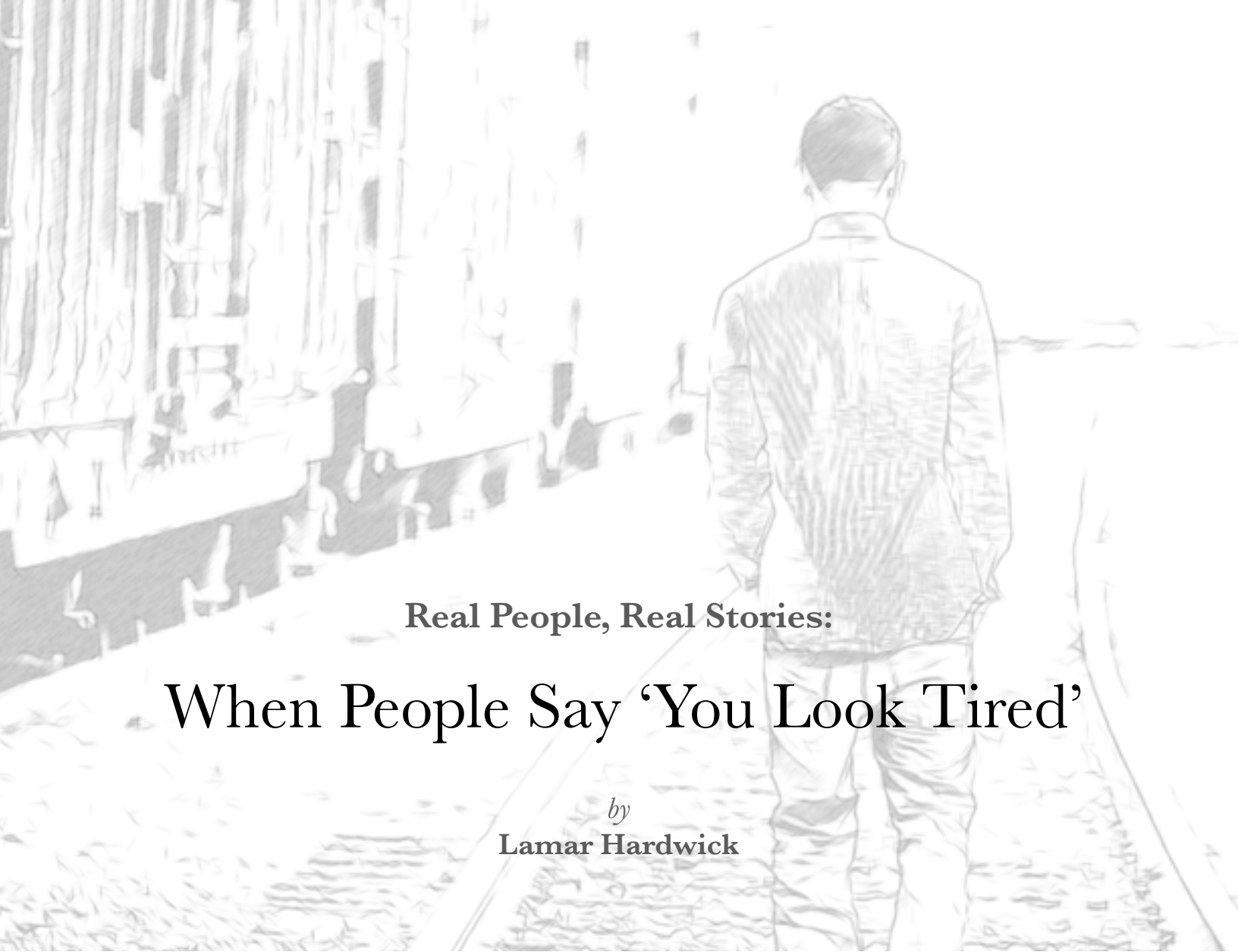
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If the World Was Built for Me



**Real People, Real Stories:**

# When People Say ‘You Look Tired’

*by*  
**Lamar Hardwick**

“You look tired.”

I don’t know if there’s ever a day I don’t hear that phrase at least once. Sometimes I hear it multiple times a day. You look tired. It used to offend me, but now I just respond with one simple answer: “I am tired.”

You see, I don’t just look tired, I am tired. I’m tired almost every time you see me. My face looks exhausted and my eyes are often red because I’m just so tired. But that’s not such a terrible thing. Let me explain why.

Living with autism spectrum disorder means I live life unfiltered. How I expe-

rience the world is completely different, and because of that it requires me to pour an incredible amount of energy into surviving each day.

My life is lived in high definition 1080p, all day every day. You may be in 480p, and that's being generous. Comparatively, my sensory processing issues mean I see, hear, feel and sometimes smell the world in ways you don't. Your brain probably filters out most of the noise, and visual distractions, and odd smells and odors because it's just not important enough for you to have to worry about. In a lot of ways your brain manages all that for you, so you don't have to be overwhelmed.

My brain... not so much. Every day I wake up I step onto the stage of the greatest production of all time. Every day it's lights, camera, action as soon as my feet hit the floor. My life is the greatest unscripted show you've ever experienced; it's bigger and brighter than Broadway.

Being autistic means my sound crew, lighting crew, stagehands, makeup crew and camera crew are all pretty much under-qualified and unskilled at their jobs. Every day I step onto the stage, the sound and lighting are so bad that it's borderline obnoxious and at times just painful to listen to and look at. The lights are often too bright or too dim. The spotlight is never in the right place, the house lighting is terrible and all of that impacts my depth perception and facial recognition. Sometimes that's why I have trouble recognizing people I've already met. This means I visually experience things quite differently than you do. It's actually a lot of work, and sometimes it's overwhelming.

So I don't just look tired, I am tired.

My makeup team is usually missing in action. My face looks worn out because I'm unable to hide behind the masks and makeup so many other performers use to hide their true feelings. My face is naked; it says exactly what it's feeling. It looks tired because it is tired.

I have no stagehands. My brain doesn't come equipped with people to help me

understand cues. I don't always know where to stand, when to enter the stage, when or where to exit the stage or even when to say my lines. I repeat myself a lot, but I didn't get my script, so usually my one-act play turns into a unique combination of improv, reality TV and stand-up comedy that feels more like a variety show than a Broadway musical. All of this takes a ton of energy.

So I don't just look tired, I am tired.

My camera crew is not a crew at all. I have one camera, which means I have only one angle, one shot and one view. I don't get to see the world through multiple perspectives, and more often than not, you don't get to see my performance from a different perspective either, so it's hard for you to see me in a different light. You see someone who isn't excited and doesn't want to be here, but you only have one angle, one shot of my performance. There aren't cameras to capture the other sides of me. Yes, it's confusing for you, but it's exhausting for me.

So I don't just look tired, I am actually tired.

But that's a good thing.

I'm tired because I've fought with the passion and the tenacity it takes to step out on that stage full of sensory overload and social anxiety and put on the performance of a lifetime.

I don't look tired, I am tired but that's good because I'm doing the heavy lifting. I'm tired because I choose to engage rather than retreat. I'm tired because I know I have something to offer the world, and to bless the world with my gifts I have to give it everything I have.

I don't just look tired, I am tired, but that's because I've found the courage to be more concerned about my assignment than I am about my appearance.

I'm autistic, and I have an assignment to show the world, to show autism parents, children and other autistic adults that we have a variety of gifts to give to



the world. I show up in the work place and the market place, ready to perform no matter how exhausting it is and no matter how unable I am to hide my fatigue. I show up every day ready to perform because the world needs my voice. The world needs autistic voices. When our voice is absent, a void is present.

So yes, I look tired, and yes I am tired, but I'm OK with that because it means I'm leaving it all on the stage.

I may look tired, and I may actually be tired, but I am tired because I've also triumphed. I've made it through another performance, and I'm excited about doing it all over again tomorrow.

So kudos to all of my fellow autistic friends, parents, colleagues and companions. Keep going. Keep pushing. Keep performing. The world needs it.

Break a leg,

Lamar



**Real People, Real Stories:**

# Someone Asked My Son With Autism Why Eye Contact Is Hard. This Was His Answer.

*by*  
**Lisa Reyes**

I received this question, through my own blog for my son, who has autism. His name is Philip.

Hi Philip,

My sister, who has a son with autism, just told me about your page. I'm a big admirer of what you're doing.

I am trying to learn everything I can about what life is like for my nephew so I can interact with him better. As I'm only just

discovering your page, I'm not sure if you've covered this topic before: Why is it so difficult to make eye contact with people? For me, it was always hard to communicate with my nephew because I used to think he wasn't paying attention since he was looking away or stimming, which made it seem like it was impossible for him to hear what I was saying. I know better now but would love to find out more about what it's like. Thank you for opening up your world to us – you are an inspiration!

I had Philip write back. He said:

I am letting you know about eye contact. My eyes see very well. Most people seem to need to have to look long and hard to make sense of a picture. I can take in a whole picture at a glance. Each day I see too many little petty details. I look away to not get overwhelmed by a lot of little bits of information. I watch things that a teacher or person I listen to tells me to watch. This helps me concentrate on what I should be focusing on. I can search for a teacher's voice to try to focus on. I am academically learning best when I sit side-by-side with a teacher. A seat on the side keeps me focused on your voice and not on visual distractions. I am assessing many sounds too. I have to erase some stimuli to access my answers to people's questions and meet their demands. That is why I don't make eye contact. I am always listening. I listen a lot to voices. I so love when people talk to me and are not talking like I am not there. I am active because I am unable to feel my body well. People think I am being rude but I can't help it. I need to move to feel my body, but sitting down at least helps me not walk away from you. Please peacefully talk to your nephew. Let him know you understand. I am sad when people think I don't like them. I love people.

Love,  
Philip



**Real People, Real Stories:**

# When People Wonder If My Daughter Really Has Autism

*by*  
**Jessica Wright**

I've seen the looks. I've heard the whispers. Nobody actually says it to my face, but I see them wonder. "Are you sure she has autism?"

People have a narrow view of autism. They seem to think they would be able to spot a child with autism a mile away. They envision a nonverbal child lining up his cars. They envision a child who can recite statistics about Mars. But that isn't the reality of my child. That isn't the experience in my house.

My child will greet you. She will say hello and make eye contact. She can be quite social and has no trouble answering your question of, "How are you today?" with a response of "fine."

But she may not be feeling “fine.” It takes effort to muster up that response. She would likely much rather be in her room with her headphones on and her heavy blankets. When you are asking her how she is, her brain may be latching onto sounds and it can take effort to quiet them in her head. The feeling of the seam on her sock may start to send an overwhelming sensation pulsing up her body, causing her skin to itch and tingle. The lights in the room may seem too bright, making her head pound. But while all of that is going on in her body, she manages to look you in the eye and muster the words “I’m fine.”

So how does she do it?

Autism in girls like my daughter can look quite unique. She has distinct instincts, so she learns to model and copy. But children with autism can have difficulty transferring information from one situation to another. She comes to learn her friend Jane thinks it’s funny when she says a certain phrase, and she may expect everyone to think it’s funny. So when Suzy starts to get upset by the same thing, the world becomes a confusing place.

The strain and stress of holding it together can become a huge weight to bear. It can become too much to contain. It needs a release. It needs an outlet. This can be where aggressive, demanding or oppositional behaviors come out — or at least that’s how it appears to the outside eye. The reality is that underneath is likely confusion and isolation and anxiety.

Autism is a spectrum. It is not a one-size-fits-all diagnosis. While the spectrum includes some general traits, those traits do not present themselves the same way in all individuals. So people will wonder and whisper and question our diagnosis.

I won’t carry around my assessment papers to prove to the skeptics that my daughter has autism. I shouldn’t have to. There should be less judging and more acceptance. There should be less questioning. So please don’t question if my daughter really has autism. Trust that she does. Trust that she is working hard to find her place in a world that can often be difficult to understand.



**Real People, Real Stories:**

# What It's Like to Deal With Eating Issues as Someone on the Autism Spectrum

*by*  
**Erin Clemens**

Some people say that when a person is hungry enough, they will eat. But this statement is not true for me. I am on the autism spectrum myself, and I have had an issue with healthy eating habits my whole life. I take a multi-vitamin daily. But I also try to find healthy foods that taste good. For example, breakfast drink powders, or juice instead of soda. Also, I've noticed that the more I'm around food that is cooking, and the more I smell the food, the more I'm willing to try eating it. However, when I'm stressed out, I find it very difficult (sometimes impossible) to eat. It's easier to sip a drink than it is to chew and swallow an entire meal. It literally hurts to put food in my mouth at these times. Both my mouth and my stomach hurt. My jaw tenses up, along with the rest of my body. And if I try to swallow, I may gag or even throw up.

I was definitely more restricted as a child. As I have gotten older, I find I have tried more foods — but it has been a very slow process. As I said before, when people cook foods I know I'm not going to be forced to eat, I'm much more willing to try them because I smell the foods cooking around me. However, forcing me to eat foods is a very traumatizing experience. I would honestly rather starve myself than eat foods that I don't like. I have nearly passed out because of that. No, I don't like feeling that way. But it's still better than putting foods in my mouth that I don't like.

It's not that I don't want to eat healthier foods. It's that it can hurt to do so. Forcing me to eat something that hurts me is only going to traumatize my eating experiences and make me want to eat less. Again, as strange as it sounds and as hard as it is to believe or relate to, I'd rather pass out from hunger than eat something that hurts me to eat it.

What helps me is to have people always offer foods and cook foods that are better options (but not the only option!) just in case. One day I may surprise you and ask for a bite! But I appreciate so much that my parents respect the fact that I literally can't eat some foods.



**Real People, Real Stories:**

# What a Meltdown Feels Like for Someone With Autism

*by*  
**Emma Dalmayne**

It's never just a sandwich.

As an adult on the spectrum and a mother of children with autism, I am often asked about meltdowns and how they feel. I can tell you how it feels to have a meltdown from my perspective and how to help your child.

When you have a meltdown, it's as if the world is ending. Everything is too much and you feel like an overwhelming darkness has engulfed your very being. Irrepressible anger that may seem completely irrational to an outsider can be inwardly devastating us internally.



When your child suddenly explodes because their sandwich has been cut at the wrong angle or another child has won a game, or even because they have been jostled in line, it's the catalyst. It's the last straw on the camel's back. It's not the sandwich, necessarily; it's a build-up of things that may have happened during the day or even previous days. That sandwich was the last thing they could control and once that erred, their world crumpled. The last bit of control over their universe disappeared.

Smashing, ripping and throwing might be involved in an angry meltdown, as well as self-injurious behaviors to display outwardly the pain they're experiencing internally.

How do I know this? Because it can take me missing throwing something into the bin or my PIN failing to go into my online banking properly and I will puddle, literally explode/implode and sob like my heart will break. It will be because of a build-up of things, and frustration will be the reason.

There's also the depressive meltdown, the one that makes you feel like you're nothing, worthless, and like the world would be a better place without you.

There's no rationalizing with someone in either of these meltdowns. If you tell us it's OK, it's not. You are trivializing our distress and it will make us worse. "Stop" or "Get a grip" are also triggers, because we would if we could; no one wants to feel this way.

If your child is self-injuring, guide the hands down to a firm surface to hit.

If they are biting, grab a chewy or clean washcloth for them to fasten onto; they may need to feel the pressure of the bite to ground them, so wind a cloth around their hand so they can bite their hand without breaking the skin. If they head-butt, get crash mats and a safety helmet. A weighted blanket works well to help regulate, as does a weighted body warmer. Offer these if you see a meltdown is on its way.

Rumbling is a sure sign, or pacing up and down or verbalising aggressively, so

redirect to a safe, quiet area, if possible.

If you are out and a meltdown occurs, the child may run. This is because we literally need to get away to somewhere quiet and sense of danger will fly out the window. If you need to restrain your child and get them somewhere safe, do so. Print off a few cards detailing your relationship to your child and the fact they have autism and are having difficulties coping, as the sight of an adult carrying or holding down a screaming, struggling child can be mistaken as abduction.

If your child has violent reactions before school or after, it's more likely anxiety and frustration at not being able to communicate what's happening. Sensory overload is also a massive trigger. The school should be making accommodations for your child, like sensory breaks and allowing the use of ear defenders, tinted lenses and a chewy if needed. Check that your child is not being bullied, as they may not even realize that you don't know that they are and may feel resentful toward you for taking them.

It's never just a sandwich.

Lastly, only restrain your child if they are a danger to themselves or others, as a touch can feel like an electric shock and may cause them to strike out with a fight-or-flight mechanism.

Too often I see posts on Facebook and articles by parents about how terrible it is to cope with a meltdown and how hard it is for them; they have no idea how hard a meltdown is.

It's about your child and how bad they are feeling. Please don't punish or berate your child for how they have reacted, as it's not willful or even conscious. Maybe they even blanked out completely, as in a full-blown meltdown. This can happen, too, leaving us bewildered at the devastation around us.

A cool drink and dark room, as well as clear, short sentences, will all help.

Remember, there's more to it than a sandwich.



**Real People, Real Stories:**

# When We Realized My Husband Has Autism

*by*  
**Jessica Offer**

My husband Cj and I celebrated 10 years of being together. Ten years since we first met. We actually have three anniversaries (yep), but this one is the one I regard to be the most important because it was this one that marks the date that life as I knew it would be tipped upside-down.

God, my husband is gorgeous. He is the most incredible father who is ever-present for his tribe of girls. He has this cheeky grin, and he has a great sense of humor and makes me laugh a lot. He's so bright. He teaches me lots of things. He also is fantastic at pulling me up when I've taken something too far, and he'll often be the first person to roll his eyes and sigh with a comment like, "Why

must you always insist on learning things the hard way?” (Because that’s me, baby, a bull in your china shop).

My husband is a 33-year-old male. He also has autism.

We were together seven years before we realized he has autism. It wasn’t until after my eldest daughter was diagnosed after a few years of back and forth deliberation on my behalf that we finally got her assessed and diagnosed — and then it occurred to us that Cj has autism, too.

I knew my eldest daughter wasn’t “neurotypical” from about age 4 in kindergarten.

Back then I didn’t drive. So we walked everywhere. If I walked a different route to kindergarten, she would fall apart. If I didn’t give warning when I planned to change her usual breakfast food, she would not handle it. She never liked to be touched by other kids in kindergarten. She didn’t cope well with singing songs. She would cry and cover her ears when someone sang “Happy Birthday” louder than a hushed tone. She didn’t give good eye contact. She didn’t cope with meeting new people very well. She was rigid in her routine, and there were plenty of routines.

I mentioned these quirks of hers to my husband. He dismissed them as “normal.” He said he didn’t see the issue.

Wanna know why? Because it was his normal, too. He saw no issue with the way she behaved because he could see why. He could understand her triggers because they triggered him, too. And he had many of the exact same struggles when he was young that she was experiencing now. But no one made any connection.

After another very tough year I decided enough was enough. I needed help. My daughter was melting down at the beach. Her screaming would go on for hours and hours. I’d tried everything, and nothing was working.

She was assessed. She was diagnosed with autism. It took a pediatrician an hour to make crystal clear of a bunch of ongoing issues we'd been experiencing as a family for almost two years. I felt relief and direction. When I told my husband he was in shock and also in disbelief.

Ever heard the phrase “can’t see the forest for the trees?” It means sometimes the most obvious answers are directly in front of you, but you just can’t see them because you’re not paying proper attention.

A few evenings later after Sno was diagnosed, my husband and I sat down on the couch together and went through her diagnostic criteria. And it was here that we discovered so many of her quirks were the same as his.

We had been together for seven years by that point. Seven years of being in love, parenting together and living together. We'd only ever had three nights away from each other. Then all the pieces began to fall into place. The reasons behind his social overload and only ever wanting to go out one weekend day now both made sense, along with his exhaustion from talking to people. Even down to the specific way he liked to organize the pantry (hey, who was I to interrupt such beautiful methodology?). We chuckled over just how many things we had automatically adapted to without even noticing.

A few months later my husband went and had formal assessments done and received his official diagnosis at age 30. He greeted it with grief, but also relief.

Which brings me to...

When I said yes to marrying my husband, I said yes to him along with his quirks (which back then I had no idea were due to autism). I loved him for the way he saw the world and how he worked within it. I loved him for the way he can fix anything that is broken, the way he seamlessly adapts to different social situations, his impeccable attention to detail. I love him for the way he can problem-solve. I love him for the way he's a straight shooter and doesn't suffer fools. His dry sense of humour.

Looking at the big picture, I guess you could say the things I love about my husband the most are probably his most “autistic” traits. Fancy that!

Autism didn't change my husband. He's never not had autism, and it's what makes him who he is. But maybe his earlier formative years would have been a lot less stressful and hard for him had his autism been recognized. He could have gained the appropriate support and learned strategies at a young age, rather than having to cleverly wing it for over 25 years.

There's a lot more knowledge about autism now, definitely more than there was when my husband was a child. I guess that's why we are both passionate about early diagnosis and intervention. Because when you love someone you love them fully and wholly and you want to support them to be the best they can be; whoever that is. And you realize labels don't define or limit a person's abilities — but they can offer great insight into the individual's personality, and enable them to be supported to reach their full potential.



**Real People, Real Stories:**

# Autistic ‘Obsessions’ and Why We Really, Really Need Them

*by*  
**Chris Bonello**

Autistic people like me are known for their “obsessions.” Be it washing machines, vacuum cleaners or dinosaurs (hell yeah, dinosaurs!!), having obsessions is seen as an autistic trait.

And therefore, it’s something unhealthy. Or at the very least deficient.

Now, people who hold those kind of obsessions usually struggle to articulate why they’re so appealing, or at least in ways the other person can understand or relate to. So allow me.

## **What's the difference between an interest and an obsession?**

Well, to be cynical: Normal people have “interests.” Autistic people have “obsessions.”

Sometimes they are one and the same — it's other people's perceptions that differ. Mainly because the way we express our love for things is less “normal” than the way others do.

For example, when I was about 7, my main interest was dinosaurs. But whereas most young children would express their love of dinosaurs by pretend-roaring and stomping around the playground, I expressed my love by telling people I wanted to be a paleontologist (and telling them how to spell it), memorizing geological eras from Precambrian to Pleistocene, learning Latin words so I knew what dinosaur names meant and reaching the stage where I could grab a piece of paper and write down 91 different species by memory. (Yes, this happened when I was in first grade.)

If teachers had known about autism back then, I'm pretty sure this would've been an “autistic obsession,” rather than a legitimate interest.

During my time in education, I ran 16 different chess tournaments in six different schools, and some of them became... er... slightly competitive. My record was running two clubs in two schools at once, each with 32 competitors. It was intense. And awesome. But mostly intense.

To those who didn't know about my Asperger's, my enthusiasm for chess was down to me being a chess geek. Among those who knew about my Asperger's, there were a small number of adults I encountered who clearly believed it was an “autistic obsession” rather than honest enthusiasm like other people have.

## **Be careful before discouraging “obsessions.”**

When I was 13, I was still a proud fan of Sonic the Hedgehog. Not just the



games either — I was still reading Sonic the Comic, despite being “far too old” for it. There were plenty of people who wanted me to “just grow out of bloody Sonic, you’re not a kid anymore.”

But... why should I?

Back at that age I couldn’t properly express how much Sonic the Hedgehog changed my life. Thankfully now I can, so here goes.

### **Sonic the Hedgehog made me an explorer.**

Did you ever play those awesome Mega Drive (Sega Genesis) games? There were often a dozen different ways you could reach the signpost at the end. Not only did this give the gamer plenty of reasons to play again and again, but it influenced my curiosity. I applied this to the forests outside my house until every single tree had been climbed and every cliff face ascended and descended again.

(And then I went to school, where I was told that our generation never went outside because of games consoles.)

### **Sonic the Hedgehog made me a writer.**

If Nigel Kitching ever reads this, he needs to know he’s a hero of mine. Sonic the Comic (Fleetway Comics) taught me that even comic strips could be gripping stories in their own right. English lessons taught me the writing skills, but Sonic the Comic taught me about the heart of writing.

### **Sonic the Hedgehog taught me never to give up.**

In the world of Sonic the Comic, Doctor Robotnik conquered the world in issue #8. Pretty heavy start. Sonic and his friends didn’t liberate the world until issue #100, three and a half years later. During those three and a half years, I watched characters I loved fighting an insurmountable foe, never giving up as long as there were people they needed to defend.

Whilst I was being told to “grow out of Sonic,” I was reading the stories, busily learning moral principles that would stay with me into adulthood — like why it’s important to stand up for what’s right even if the odds are against you.

If there’s one thing I want people to take away from this article, it’s this:

**Before you encourage autistic people away from their obsessions, make sure they aren’t actually legitimate interests which are secretly doing them a world of good.**

If you believe in parallel universes, there’ll be a universe where I obediently cast Sonic aside. In that universe, I’m not starting an MA in Creative Writing because I never wrote all that fan-fiction that got me off the starting blocks. In that universe, I never learned how to explore everywhere, whether locally or internationally.

In that universe, I’m less willing to stand up for what’s right.

Next time you see an autistic child “obsessing” over dinosaurs and you personally don’t like it, think about the parallel universe in the future where the child doesn’t become a paleontologist.

We have the same love of things as everyone else. We just express it differently. And sometimes we rely on those interests more, especially if being popular in social groups is off the table. Losing an interest because of other people’s perceptions would simply be another reminder of why we’re not good enough.

And besides, dinosaurs are bloody awesome. Let us love them.



**Real People, Real Stories:**

# My Answer to the Question ‘What Does Autism Feel Like?’

*by*  
**Lori Sealy**

One of the questions I’m most often asked by parents of people living with autism (and one of the questions I’m honestly most afraid to answer) is “What does autism feel like?”

My fear comes from two places.

The first is that I never want anyone to take my personal experience of living life on the spectrum as being the universal experience of living life on the spectrum. My story is just that — my story, and while there can always be common denominators in the autistic experience, there is also much diversity. That’s why they call it a spectrum.

Dr. Stephen Shore once said, “If you’ve met one person with autism, you’ve met one person with autism.”

The specific ways that autism feels and manifests in me may be very different from the specific ways in which it feels and manifests in someone else. So, I’m sometimes afraid to say how it feels because I don’t ever want to be set up as the “autistic standard.”

The second source of my fear is that there have been some folks who’ve just not been very nice when they’ve learned what life’s actually like for me. I’ve been called “crazy” and “cuckoo” and “a couple of fries short of a Happy Meal.” I’ve been labeled a lunatic and laughed at by those who really should know better. I’ve had people talk terribly about me behind my back — not knowing their words would eventually make their way to my face... and more painfully, to the center of my heart.

Their cruelty has made me cautious, and there have been times when I’ve considered catapulting myself away from this public perch as an autism spokesperson.

Every time I prepare to turn tail and run, I inevitably receive an email from a mom who’s hurting and confused and trying desperately to find one tiny hook to hang her hope on as she battles what is tormenting her child. She asks me to help her understand even an ounce of what her little one might be feeling, and I realize that I can’t allow mean comments or the face of my own fear to silence this story.

So, today I go to that place where I’ve often feared to publicly tread.

**What does autism feel like in me? Well, autism often feels awful.**

Before I give you some specific examples from my own existence, let me make sure that you understand what autism spectrum disorder (ASD) actually is.

Autism is a neurodevelopmental disorder that is often characterized by varying degrees of struggle with social interaction, verbal and nonverbal communication, sensory processing, and restricted or repetitive behaviors. I'm going to break some of that down for you — at least as some of these things manifest in me — but I want you to recognize that all of the “psychological” manifestations that you see in a person with ASD actually flow out of the underlying neurological system of ASD.

The behavioral chicken hatches out of the physiological egg.

That's important to understand, because when people with autism seem to be “behaving badly,” it's often because we're hurting badly.

## **The Frayed Wire**

I often explain the neurological framework of autism (the framework from which autistic behavior flows) by likening the physiological pathways of the autistic body to that of a frayed stereo speaker wire.

Everyone with autism has some form of sensory struggle. Sight, sound, smell, taste and touch (the five senses that all of the experiences of life must pass through) can be absolutely harrowing and horrifying to a person with autism. Everything that enters the ASD body is often accompanied by some semblance of pain or at least by some extremely uncomfortable sensation. Here's where the analogy of the frayed wire may help you understand autism a bit better.

When you go to your stereo and turn on the tunes and all is working well with the speaker wire, then the sound is sweet, crisp and clear. You hear what the artist and producer intended for you to hear — and it's a good and pleasant thing.

However, if your speaker wire has a short in it, if it's frazzled by a fray, then things might not go so well, and a clear connection could be lost.

There are moments when that frayed wire may be in the perfectly placed position to still allow really solid sound to pass through. In that moment, the music

is coming through loud and clear and you get to enjoy the groove.

But then something shifts — even just a little, and suddenly that worn wire produces static (and maybe even sparks). The music's still there, but with it is another competing noise — a sharp and crepitating noise — a noise that's taken something pleasant and made it painful.

All of a sudden something shifts again, and everything has gone from simple static to overwhelming and excruciating white noise. In the chaotic cacophony you find yourself reaching for the volume control in order to mute the mess because it hurts.

Then things shift once more and the frayed wire is now in a position where nothing's getting through. The connection has been lost and all is silent. The stereo itself is still making a melody, but that melody is trapped inside the machine and unknown to anyone on the outside.

Welcome to autism!

Our neurological wiring — the “speaker cable” through which the five senses travel within us — is “frayed.”

At one point we're positioned so that the things of life are coming through clearly and we may almost seem OK and maybe even “normal” — our melody might momentarily sound marvelous.

Then the wire wiggles and begins to produce some static — and we become confused and stressed because we're trying to hear the “tune” of our surroundings over and against the torture of the snap, crackle and pop of the crimped cord.

Suddenly the wire is all static and we're utterly undone — because the racket is just too much to bear and we're suffering from the neurological distress.

And then there are those times when the connection gets completely cut and we

find ourselves disconnected from the music and meaning of life. The tune is still in our head — we just can't get it out for you to hear.

The “frayed wire” that is autism is not a pretty place and is often a painful place.

I'd encourage you to remember this analogy when you see a person with autism struggling with a shutdown, or a meltdown, or an absolute disconnect to his or her environment. The neurological wire's not working well. We're not “insane” — we're in pain! Please have some mercy in the midst of our malady, and show a little compassion to us (and to those with us) as we seek to navigate the nightmare.

### **My Own Experience With Autistic Angst**

The personal pieces of how autism's “frayed wire” fleshes out in my daily existence, well, those are varied and would take a lot of time to walk you completely through — but I'll give you a glimpse and will trust that you'll love me and not laugh at me as I un-bear my burden.

My hope is that this will help you understand a bit more about life with autism, and that as your understanding increases so will your heart for those who are hurting — no matter how they hurt.

Where the sensory is concerned, much of my life has been lived without filters attached. For many people, the brain naturally sifts and separates visual, auditory, olfactory and tactile information. Your brain is able to decipher and discern what's important to focus on and set aside that which is less relevant at the moment.

In my experience with autism, everything flows through with equal force. Life is like a continual sensory storm. A raging flash flood of sensorial data is always pulsing through the marrow of my bones. It's a never-ending, devastating deluge of chaotic kinesthesia. There's no sensory spillway; a dam's not even dug to help control all that's pouring into me. Everything hits me full on, and I've had to learn to sink or swim against the surging onslaught of my five senses.

Where sound is concerned, the voices and vibrations of this world are always pounding upon me. Life is loud! This can make carrying on a conversation in a room full of people a true challenge — because I hear everything at equal volume. My auditory abilities are often extreme. In that room, I hear your hair. Yes, you read that right. In a room full of people I literally can hear when someone's hair moves in the wind or when they brush their fingers through it. In that room as you and I are trying to talk, I am hearing everyone else's conversations as clearly as our own (along with their hair!) — and that's a confusing thing, because which words am I supposed to be interacting with as we chat? Take that scenario and apply it to the classroom, the park, the church, or Walmart. It can be absolutely overwhelming!

As a young child I was barely able to eat in front of others (many assumed I had an eating disorder) because of the pain I felt when someone's fork touched their teeth. In a restaurant, I was always undone because not only did I hear multiple food implements on everyone's incisors, but also all of the kitchen noise, and chewing, and swallowing, and breathing, and the transfer of change at the cash register, and the hum of the fluorescent lights, and everyone's clothes making contact with their chair (oh yes, and their hair!) — on and on and on it goes.

The amount of auditory information that my brain was processing was overwhelming and it usually resulted in a panic attack — even at the age of 8. Everything that I heard hurt — it still does. By grace, though the years I've been able to develop some coping skills that now allow me to handle this a bit better — or sneak away when I know I can't.

My visual experience is also rather radical. Bright light can be painful — honestly, any light can be painful and I often compensate with sunglasses. I can also get overwhelmed by the sheer amount of imagery that my mind is attempting to process at one time. I take in everything in a panoramic sense — and that sometimes makes it hard for me to focus on the central thing I'm supposed to see. I've found that wearing a ball cap helps me filter, by force, that which is crashing in by flood — it works in the same sense that “horse blinders” do at the race track.



One of the unique and challenging aspects of ASD for me is that my neurological wiring has an odd criss-crossing of visual and tactile. I feel what I see. When I look at a tree, I literally feel the bark. When I see a wall or a chair (or your hair), my body senses its surface. When I read a book, I feel the page. The same is true when I see your face, yes, I feel your face... which is one piece of the problem that some with ASD may have when looking others in the eyes.

Take a moment and look around.

Think about what it would be like to feel everything your eyes see. Welcome to my world!

My panoramic vision and the accompanying deep memory vault that can often be part of autism have an interesting correlation. I view life in pictures and my brain categorizes and catalogs all that I see.

Everything I look at goes into what I call the mental “file folders” of life. Things are subconsciously stored in my mind, in vivid detail, and under specific headings — I’m not able to always call things up on command, but I regularly experience a meticulous mental “finger-flipping” through the files of past experience when I enter a similar situation.

For example, when I walk through the door of my house, my mind flips through the pictures of every other time I’ve ever walked through the door of my house. It’s an involuntary visual occurrence that at times can be overwhelming. When I grab a shirt out of the closet, I relive where it came from — even down to the rack at the store where I found it and what other shirts hung near it, as well as all the other times I’ve worn it.

I may sit down for a haircut and in a matter of moments relive every other hair cut I’ve ever had (in great detail: the number of combs or brushes on every counter, the pattern of the tile, the position of the pictures, the people congregating for a coiffure). The same could be true when I go to a drive-in window, play a piece on the piano, or see you in the grocery store. Please realize this if I seem startled when I run into you somewhere — I may be reliving our entire

relationship!

One tough aspect of that deep “file folder” memory, as it’s coupled with the disconnect of autism’s frayed neurological wire, is that sometimes it can be hard to moor myself to the current moment. There are times when I have to fight in order to determine which picture I’m seeing is the current picture. Which image is the here and now? Is this scene of life “live or is it Memorex?”

In light of this reality, I sometimes feel like I’ve never fully lived a moment of my life (the frayed wire), nor ever truly escaped one (the visual file folders). And that can be really hard at times.

Where touch is concerned, I often physically feel things from the inside out. When you touch my flesh, the first sensation that I have is from the center of my bones — and it can be rather fiery — anything from a dull burn to extreme electrocution. That feeling then flows backwards to my skin, at which point it’s usually not quite as painful.

Often when someone shakes my hand, or pats me on the back, or kisses me on the cheek, I will feel that sensation for at least an hour before it fully dissipates.

Clothing can hurt to wear.

Sheets can hurt to cover up with.

The most intimate forms of affection can be a great affliction.

There are times when the internal terrorism of the tactile makes me want to rip my bones from my body — which is one of the reasons you’ll often find those of us with autism engaging in some form of stimming (rocking, flapping, finger flicking) — it’s our attempt to counter all that is caustic.

Because I speak and sing for a living, people are often shocked to learn that I struggle with issues of communication — verbal and nonverbal.

My verbal abilities have been honed through years and years of hard work (my mom used to drill me on the practice of public speaking over summer break). In spite of the success I've had in overcoming my struggles, throughout my life there have been many seasons of selective mutism. Honestly, in certain settings there are still those moments of selective mutism, because I know the "wire" isn't working well and that my attempts to talk aren't going to end well. So I simply don't talk. To me, silence has always been a virtue of self-survival.

When I do talk, I constantly coach myself in order to make my mind and my mouth correctly connect. Speaking is not an unconscious or habituated thing for me (really nothing is a habituated thing for me because I think through every action in great detail).

My talking to you is an exercise in extreme self-control and a labor in almost Nietzschean "will-to-power," which can be exhausting — and which is one of the reasons I can only endure so much conversation before I have to bail. Sometimes I realize I can come across as a little bit rude — it's because I'm worn out from words. That's no excuse for sinful behavior, but perhaps it will help you understand my struggle with that behavior.

Because my mouth and my brain don't always work well together, I have found it much easier to allow my thoughts to fly from my fingers than to leap from my lips. That part of my "wire" isn't nearly as frayed and is definitely my preferred form of communication.

Where the nonverbal is concerned, there are so many stories.

As a young child, I spent hours in front of the mirror teaching myself how to really smile. Even now, there's a "director's voice" in my head where I walk myself through which learned facial expression is the appropriate one for the moment. My vault of "file folders" is part of what now helps me read other's expressions accurately — I automatically pull up other encounters with laughter and sadness and seriousness, and then apply that "photograph" to the current event.

I also trained myself to look people in the eyes at a young age. From my earliest days I can remember my neck shaking and my head drifting down when someone's eyes would “touch” my own (an eye “touch” is what it felt like, and it was incredibly uncomfortable — it was moist and squishy and made my skin crawl).

As an elementary-aged child, I forced myself to sit in class and stare the teacher down from a distance. When my neck would begin to shake and when my eyes started to drift, I would push all of the pressure of my neck muscles down through my body and into my toes — establishing a form of muscular “toe transference” that I still use to this day as a primary form of autistic coping.

I could talk to you about so many other things: strong seizure-like moments where my brain seems to shake in a violent fashion or petit mal periods that steal away sections of my day. I could discuss why at times I hit my head, why running is almost impossible for me, how monocular vision may possibly be playing a role in my inability to determine depth, and how hard I've had to work to learn to develop empathy for others — because emotional understanding, for me, has been an autistic anathema that only the mercies of Christ have helped me overcome.

What does autism feel like?

In me, it feels like all of this and more.

What words will ever adequately explain?

I know them not.

What I do know is that through every autistic “danger, toil and snare” through which I've already come, “'tis grace has brought me safe thus far, and grace will lead me home.”

In that grace, I find a sufficient salve for all of my autistic suffering. And as I've given the smallest glimpse into my own version of autistic angst, I truly pray that you have increased in even the smallest sense of autistic sympathy!



**Real People, Real Stories:**

# When a Boy With Autism Asked Me What It Was Like When I ‘Had Autism’

*by*  
**Amy Gravino**

Last year, I was asked to be a guest speaker at a middle school in Brooklyn for their Peace & Diversity Conference day. I spoke there to a group of sixth-graders and then had lunch with a self-contained class of sixth-graders with autism. I was asked to return again this year, and I made the trek out to Brooklyn at the end of January, just hours ahead of a snowy winter storm.

I can still see him so clearly.

The small one, with thick, black-rimmed glasses that were almost too big for his face, sitting there tugging nervously at the hem of his shirt. He wasn't as

gregarious as some of the other children — not like the one I affectionately refer to as Mr. Mayor, because he probably will be one someday — but he made an impression I won't soon forget.

It's not often I have the opportunity to be around sixth-graders, let alone ones who are as self-aware and bright as they were. One by one, they came over to sit at my table and began asking me questions in that combination of wide-eyed innocent and weathered only 12-year-olds seem to do so well. They sometimes spoke over each other, and as their enthusiasm grew, the questions flew out almost before their brains had a chance to finish coming up with them.

Then it was the small boy's turn. He cleared his throat and looked up at me shyly.

“What was it like when you had autism?”

I pause.

“Well... I still have autism,” I said, the full weight and meaning of his question just starting to sink in.

It's no secret that most of the media portrayals of autism predominantly feature young children. Autistic adults are given very little of the spotlight in comparison. But perhaps there is more to it than that.

Every day, many children with autism undergo various types of therapies — ABA, floor time, social skills groups and so on. Self-contained classrooms are cropping up in schools all across the country, accompanied by a veritable army of teachers, psychologists, speech therapists, aides and other professionals. All of this in the name of helping these kids overcome challenges, thrive and succeed.

But increasingly, “success” seems to be defined as “no longer appearing to have autism.” Parents, teachers, people with the very best of intentions are doing a great disservice to children with autism if they send them the message that this is only temporary, something they are getting help for now, so that they — and

everyone else — won't have to deal with it later.

In reality, nothing could be further from the truth.

As a child, I did not undergo early intervention. My parents tried one thing after another to help me, a desperate if not futile effort in a world that had little (if any) awareness or understanding of autism. The challenges I faced were many, yet few were greater than the low expectations and doubt in my abilities that others had for me.

Today, I am an autism consultant, a professional public speaker, a writer and an advocate. I've surpassed the beliefs of those who said I would not amount to anything, who told my parents I would not graduate high school, let alone attend college. I have a Masters degree, I have my own business, and I have a life that took me years of struggle to build. My story only started because I believed it was worth writing, and even now, it is still being written.

I have overcome tremendous obstacles because I have worked hard to do so, not because I no longer have autism.

The fear of children with autism facing certain challenges for the rest of their lives is overwhelming, and it's often the driving force for parents and teachers to find help for these children. But because autism is an integral part of who we are, overcoming those challenges does not and will not suddenly make us neurotypical. It just means we grow up and might have those challenges replaced by new ones.

Therapies have their place and can be meaningful and effective tools for assisting autistic children and their families. But preparing your child to be an adult with autism is the best and most important thing you can do to help them live in this world.

I hope I will get to see that little boy with the thick-rimmed glasses again.

I hope he grows into his striped shirt, grows into the person he's going to be-

come, a person who will give so much to this world. I hope he knows how special he is and that he can be autistic and succeed, be loved, be a friend and be just exactly who he is.

All of our children can.





**Real People, Real Stories:**

# If the World Was Built for Me

*by*  
**Rhi**

If the world was built for me, there would be nothing “wrong” with me. I would be happy and safe and certain and successful.

If the world was built for me, when I met people there would be no expectation of physical contact or small talk. We may ignore each other with a socially acceptable nod, or throw ourselves into a deep and meaningful conversation.

If the world was built for me, we would all sit next to each other, not opposite. Things would be based on literal words, not guessed expressions and gestures.

If the world was built for me, there would be a compulsory day off for everyone after any social event. Just so we could all take the time to recharge and process things.

If the world was built for me, work would be about working and nothing else.

There wouldn't be the necessary interaction that goes with it. My productivity would skyrocket. Working days would shorten. Free time would be shared.

If the world was built for me, you'd ask me why I'm constantly fiddling with a piece of whatever it is I need that day, and I'd tell you with a smile. You'd chuckle and accept it. I'd like you more.

If the world was built for me, noise cancelling headphones would be handed out in crowded places, trains would be bigger, people would be banned from touching people they don't know without permission. (I don't mean criminalized. We have that, and it doesn't work. I mean magically banned.)

If the world was built for me, I could touch and revel and find joy in the textures that please me. And I could hide from and keep away from those that fill me with pain and revulsion.

If the world was built for me, you wouldn't ask me how your clothes look, unless you want my honest opinion.

If the world was built for me, there would be an airlock between my home and the real world. A buffer zone for daily encroachers. An arm's length.

If the world was built for me, any invitation would come with a detailed plan of where and when and how. I would be able to construct a plan and a map with little extra effort from me. I would know what was happening.

If the world was built for me, people would let me know if plans needed to change. They would message me and minimize the pain in my head as I grind the gears to adjust.

If the world was built for me, family gatherings would keep me safe. Touching, hugging, kissing, would all be on my terms. Talk would not make me feel alien and alone. It would be safe and kind and loving.

If the world was built for me, real rules would be explicit, and fake rules would

come with an explanation. I wouldn't find myself following rules that everyone else knows aren't real.

But the world isn't built for me.

It's built for people who like those things, or can cope with them, or don't like them but don't mind, or don't like them and can say they don't like them, for reasons that are valid in the world of everyone-else.

The world isn't built for me. So as the person with a brain that isn't the norm, I have to find a way to fit.

I sometimes wonder if you would like my world, with its gentle structure and routine, its beauty and its simplicity, its honesty and its truth, its patterns.

I sometimes wonder if I'd miss your world if it went away. As exhausting and painful as it can be, like cold, blunt metal, all ridged and hard to lean on, it has its charms. It has its moments. It has its joys.

If the world was built for me, I would make sure the world could be built for you too.

# Authors



## Lamar Hardwick

Dr. Lamar Hardwick is a husband, father of three boys and a pastor of a church located in Lagrange, Georgia. After decades of struggling with social disorder symptoms, Lamar finally received answers and insight after being diagnosed with autism spectrum disorder in 2014 at age 36. Today, he reaches thousands through his sermons, speaking engagements, and his blog about being a father, husband, and leader in his church and community as an autistic person. You can read more on his website [i-am-strong.net](http://i-am-strong.net).



## Lisa Reyes

Lisa's son, Philip, has nonverbal autism and uses a letterboard to participate in academics. His hobbies include swimming, soccer, reading biographies and expressing his views on his blog at [www.faithhopeloveautism.blogspot.com](http://www.faithhopeloveautism.blogspot.com)



## Jessica Wright

Jessica Wright is a mother of four. Her daughter was diagnosed with autism at the age of 10. She is finding her way through the diagnosis and along the way opening up her eyes to view the world through the lens of autism.



## Erin Clemens

Erin Clemens is a 27-year-old woman on the autism spectrum. When she is not in school or working, she likes to spend her time volunteering and watching “The Ellen DeGeneres Show.” She is also the author of the book “[I Have Asperger’s](#).” You can find more information about her on her website [aspergersadie.com](http://aspergersadie.com).



## Emma Dalmayne

Emma Dalmayne is an autistic author and a home-educating mother to her two youngest children — her 7-year-old with complex needs and her undiagnosed 2-year-old daughter. She loves writing and is an active autism advocate. She has also written the book “[It’s an Autism Thing - I’ll Help You Understand](#)” and a children’s book, “[Susie Spins](#).” You can find out more on her website [autisticdalmayne.com](http://autisticdalmayne.com).



## Jessica Offer

Jessica lives on the Sunshine Coast with her wonderful husband and four spirited daughters. Two of her daughters have autism along with her husband, and two of her daughters don’t. They’re all awesome! It’s her aim to educate about girls with autism, normalize breastfeeding, embrace attachment parenting and homebirth and empower her daughters to live to their potentials and be their true selves. She also hopes to share moments where she finds her happy.



## Chris Bonello

Chris Bonello is a former primary school teacher from Nottingham, England. He was diagnosed with Asperger syndrome at the age of 25, after growing up believing he was just socially inept. After being followed by autism in both his personal and professional life, he set up [Autistic Not Weird](#) to inform and help those affected by autism. He also gives seminars regarding how to provide for people across the spectrum.



## Lori Sealy

Lori Sealy is a wife, mom, musician and conference speaker who lives with autism both personally and parentally. She and her 13-year-old son are both on the autism spectrum. Lori and her husband Phillip live in Cullowhee, North Carolina with their family — Josh, Elizabeth, and a hyper hound dog named Murdock. You can find out more about Lori on her website [lorisealy.com](#).



## Amy Gravino

Amy Gravino, M.A., is a certified autism specialist and the president of A.S.C.O.T. Coaching. Amy is an autism consultant, college coach, writer and professional speaker who has spoken at conferences across the country and at the United Nations. She is currently authoring “The Naughty Autie,” a memoir of her experiences with dating, sexuality and relationships as a woman on the autism spectrum and serves on the awareness committee of Autism Speaks. Find out more about Amy at [amygravino.com](#) or her blog [amygravino.blogspot.com](#).



## Rhi

Rhi is a late-diagnosed autistic woman. In her late 30s, she finally understands her motivations and sees post-diagnosis as a whole new, positive chapter in her life. She loves writing about her experiences. You can read her blog at [autnot.wordpress.com](#).

# *The* **MIGHTY**

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