

CROSS TALK

Autistic in a pandemic: Stories from around the world

BY SPECTRUM

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In England, a basket on the porch becomes a purgatory for deliveries deemed perilous. In Spain, families don blue ribbons to silence the ‘balcony police,’ who jeer at passersby they think may be breaking the local ‘stay home’ advisory. In India, a child puts his fears into pictures, drawing a round blob with spikes in a tableau of sickness and recovery. In Dubai, Portugal and elsewhere, teachers and students work out a new form of school, seeing one another only on computer screens.

These snapshots of life during the coronavirus lockdown come from autistic people or their parents, around the world. *Spectrum* journalists interviewed some; others sent us their stories in response to a social-media call. In total, 22 people in 19 countries told us how the initial weeks of the pandemic have challenged and changed them. (Several contributors have withheld their last names to protect their privacy.)

Their stories reveal some common truths: No matter who you are or where you live, routines are an important part of life. The pain of change is real, and in many ways autistic adults have **felt this pain** more intensely than their neurotypical peers. But change can also bring growth. One autistic child is learning to cook; an autistic teenager is penning poetry again; and another boy is just starting to express his emotions on a digital platform his teachers created in early March. Many autistic people, who typically cling to routine, are — like everyone else — learning to live with uncertainty and to let the future flap in the wind.

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With reporting by Brendan Borrell, Linda Nordling, Ingrid Wickelgren, Marta Zaraska and Lina Zeldovich

Select any point on the map to learn more about an individual living with autism in that country.

Brenda Tan

mom ,Singapore

Cape Town, South Africa - Nicolette Ripepi, mother of Tyler, 15

Tyler thrives on movement. He loves being outside and going for drives. But under lockdown in South Africa, we are not even allowed to walk inside the complex where we live. Tyler's sleeping patterns have become erratic, and he's had some meltdowns. One neighbor has complained that Tyler is banging on the walls with his fists. The first two weeks were the most challenging. There are no special rules here for people with autism during lockdown. I spoke to Tyler's doctor, who sent me a letter giving us permission to be outside that I can show to the authorities. She said to take him out, go for a drive. I took him for a long, slow drive along the coast. Tyler loves feeling the wind, so I rolled the windows down and he put his hand out, as he does when I drive him to school. We were out for about an hour, and it helped him. His school, Autism Connect, which I helped set up because there were no services for children with autism in my area, is trying to move to online learning, but not all of our parents have access to the internet. In addition, the school is losing income because parents are not able to pay the fees — many have been retrenched or are simply not getting paid. It's a message that needs to get out: The special-needs community suffers a lot in situations like this.

Piotr NA

teen,Poland

Accra, Ghana. Serwah Quaynor, mother of Nii Nortey, 38

When I returned to Ghana from the United States in 1998, people said autism was a rich man's disease. But I helped start the first autism center in Ghana, and in the past 22 years, many children

with autism have come through our doors. The COVID-19 pandemic has affected my son's routine. He has tried to hit his head, a behavior I haven't seen in a long time. He has torn up three shirts. That's where he puts his agitation. But he knows his boundaries. He can do his own dishes; he can do laundry; he can iron; he can sew. I gave him a needle and thread and told him to stitch one of the torn shirts back up. Still, he has handled lockdown fairly well. It's me who is afraid. I worry about how long the lockdown will last. And I'm afraid for the children. Already parents from the center call me, at their wits' end. I worry about abuse — not by the parents, necessarily, but by other people in the extended family or in their area, people who don't understand. All the gains that we have made with these children, are we going to lose them?

Lise Larriviere

mom, France

Dubai, United Arab Emirates - April McCabe, mother of Owen, 16

The nights are the toughest. Owen's brain is not challenged during the day anymore, so it's going on and on all night. He is clanging around in his room, keeping everyone awake, and coming into my room. His special-needs school closed weeks ago already — first for a two-week spring break, then because of the virus. Now he has classes over Zoom. They have mindfulness and exercise sessions for everyone, as well as small classes for him and three other students, with two teachers present. We also get assigned activities for the day on an app. It's been challenging, trying to teach a nonverbal child over Zoom. I have to help Owen a lot. And it's also been quite eye-opening for me, seeing how much work still needs to be done toward his everyday functioning. But overall, things have been quite calm. There's been no hoarding in grocery stores, and we have very few cases. Besides, there's been one surprising benefit to all this: Since schools went online, we are now allowed to use videoconferencing apps, which the government had previously banned. We can now video-call our families outside Dubai, which is helping a lot. Ironically, things have opened up for us now.

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Tel Aviv, Israel - Nadia Chegay, mother of Mark, 15

Mark read the coronavirus news, so he understood what was happening, and that fueled his anxieties. He couldn't distinguish real news from rumors, so I suggested that he read only trusted sources, such the Ministry of Health website — and that helped. The other challenge was losing the regular schedule. Before the lockdown, a bus took Mark to school, and on certain days we went out for pizza. Setting up a new routine was crucial. Remote learning certainly helped, but so did giving Mark new responsibilities. Now he empties the dishwasher every morning. He's also responsible for making sure we have bread in the house. When we run out, he puts on a mask and gloves and walks over to a nearby store. He started helping me cook, and it became a new hobby. He doesn't like to cut onions, but otherwise he's really good at it. So far, he's made a sauce for lasagna, cutlets and schnitzels. He's even baking bread! I now telecommute, so his help has allowed me more time for my work. Surprisingly, the quarantine has had some positive outcomes for us.

Republic of Singapore. Brenda Tan, mother of Calder, 15

Calder loves public transport. We used to take the bus and train every weekend, but now we cannot. When the government stipulated that there should be no gatherings of more than 10 people, our Sunday church service moved online. Fortunately, Calder seems happy listening to us sing worship songs to the video. His school is moving online, too, and I can already see how he might get restless. If I didn't come up with lots of activities for him, he would just play word search on his phone until he became agitated from boredom. I try to keep him busy — making hamster bedding for his younger sister's pet, practicing piano, hanging the laundry, cutting beans or mushrooms for dinner. I am grateful as long as he stays calm and the family is healthy.

Kolkata, India - Priyanka Guha, mother of Inesh, 11

My son is curious about the pandemic, why we are all holed up at home. Once I explained the virus to him, he began drawing it, which is his way of expressing himself. The biggest challenge for us has been the disruption of our routine — something we've painstakingly created over the years and is now completely gone. My son, who had attended school and therapy sessions, who went on walks and grocery shopping, is now confined within the walls of our home. But there are positives. I'm working from home, and as a result I can spend more time with my son. These days we do things together that I could not have done before. And although Inesh's verbal stimming increased right after the lockdown and his concentration was poor, he is now much more settled. He cooks, bakes, and yes, is on screens more than before. But I see that he has made peace with the situation.

Osaka, Japan - Masae Nakatani, mother of Aki, 31

Because of the coronavirus pandemic, we have to be more vigilant about hygiene than usual and are restricted from a lot of outings. This has been the main source of inconvenience and worry. When my daughter comes home from her support program, I get her to sanitize her hands and take her jacket off at the front door, wash her hands and gargle in the bathroom, and sanitize the tablet device and other things she uses in the program. I have put these things on her schedule and make sure she follows through. We have stopped all our outings on the train and other public transportation, so we try to come up with fun things to do at home, such as cooking and baking. We have also incorporated moderate indoor exercise and stretching into our daily routine to maintain a regular schedule and enhance the quality of our sleep. As parents, we think we might be in this situation for the long haul, but our daughter is sensitive to the subtlest change in our mood, so we try our best to stay calm and set aside the time to enjoy ourselves and laugh about things as a family.

Kochi, Japan - Kazuko Kamimura, mother of Yoshiki, 20

My son does not understand the concept of hygiene, so I have been spending more time watching over him to make sure he maintains good hygiene. He likes washing hands but cannot do a thorough enough job, so I have been working on hand-washing with him. We have had to cut back on the activities with caretakers and have fewer opportunities for outings. We are anxious about becoming infected. I have a heart condition, which puts me at high risk. My husband lives away from home for his work, and our elder son lives with me, so if one of us becomes infected, we would not be able to keep living the life we currently live.

Hiroshima, Japan - Satoko Masutani, mother of Yuta, 19

At the start of the pandemic, my son's support program incorporated staggered work hours, which really threw him off because he now had a big chunk of free time to fill in the morning. So we changed his schedule so that he would take a walk in the morning and walk straight over to the program. This calmed him down, and he is now able to commute on his own. The biggest difficulty I faced was how to communicate unexpected schedule changes to him. I handled this by having him mark the new commute time on his calendar. Because we hear the word 'corona' on the news, every time I tell him about a schedule change, he asks me whether it is because of "corona." I have taken this opportunity to give him a proper explanation of the coronavirus. He is good at adapting to a new schedule, so when I added the wearing of a mask and a temperature check to his routine of hand-washing and gargling, he got used to it right away. Rather than starting new projects, we have been changing our usual household tasks, coloring and puzzles to make them more difficult or slightly different, as well as pursuing the study of music, mathematics and Japanese — Yuta's areas of interest. We wonder how long this will go on, whether we can go back to our old way of life, and even if we can, how we will readjust after a long period of disruption.

Buenos Aires, Argentina - Carina Morillo, mother of Ivan, 19

We've been under a strict quarantine since 20 March and are lucky to be in a house with a pool. Ivan loves water, and the weather has been nice. Compared with other families we know, we have had it easy, but this weekend I was really feeling weird. I wanted to go back to my normal life. I wanted to see my parents. Ivan is used to seeing his practitioners. He's been with them a long time, and they are like family. The teleconferences have been very unsettling for him. He doesn't understand why he can't see these people face to face. On Friday, out of the blue, he started crying. And Saturday the same thing happened. He is nonverbal, and although he has great comprehension, the picture-based communication system we use doesn't work well for abstract ideas. I looked at him and said, "I know what you are feeling, because I am feeling the same thing. I feel uneasy, but things will be all right one day." All of the sudden, he looked at me, and then he looked at the communication device. He pointed that he wanted to play with his ball.

Antofagasta, Chile - Josefina Troncoso, 25

I have just returned to my family home in Antofagasta, Chile, from the United Kingdom, where I attended university and have been living for about seven years. I have had a strange time adjusting to life in Chile and to its response to the COVID-19 crisis. It overwhelmed me that the advice in Chile wasn't clear from the start and kept changing with every government press conference. For example, was it okay not to wear a mask in Chile, or was going without a mask seen as disrespect? In my home, though, I am fine, since I don't have contact with others in the house and the rules are easier to follow, with less hand-washing and no need to wear a mask. Autistic adults in the U.K. were already having conversations as to how the pandemic would affect autistic people

and whether the rules could be adjusted to our needs. I hadn't noticed any such conversations in Chile until World Autism Awareness Day on 2 April. Even then, though, autistic people weren't leading the conversation: On the news, the mother of a young autistic boy said her son was jeered at for going out on walks, and an autism specialist said we were "anxious children" who "relied on walks." Not a second of that interview covered the needs of autistic adults. Make them wear something blue to let others identify them, they said, because "they don't understand what's happening." It was an incredibly paternalistic statement that showed me that there is still a widespread belief that autism is a childhood condition that deprives a person of autonomy.

Vircelli, Italy - Francesca Debernardi, mother of Federico, 11

The lockdown came suddenly. Our government did not act quickly enough, so we didn't have a chance to prepare gradually. This was very traumatic for everyone. We find social isolation difficult, since we are usually very involved with friends and family. Federico's father suffers from health problems and has chosen to go into solitary confinement. Federico hasn't been able to see him for the first 40 days of the quarantine. Same for Federico's grandparents — to protect them, we have to stay away from them. It's painful to have to keep our distance.

The schools closed on 26 February, and I worried that the loss of contact with his peers would mean a huge step back for Federico. Yet instead, he became involved with his friends through a digital platform his teachers created, and the other children started expressing their emotions. Following their example, Federico did the same. The classmates closest to him asked him if he had a phone, and so he asked me for one. I would have bought 10 phones, I was so happy! His classmates entered him in chats, and every day they have a video call together. I never thought that this isolation would be the most effective way of bringing about a change in Federico.

Warsaw, Poland - Dorota Próchniewicz, mother of Piotr, 25

Every day Piotr wakes up hoping things will be different, that he will be allowed to go out of the house again, to the nearby forest, his favorite pizza place, activities downtown. We've always been the kind of family that goes out and does stuff. Three weeks ago, that changed almost overnight. Even the forest is closed. No one comes to our house anymore, either. We could do therapy over Zoom, but Piotr is not interested — his communication skills are not very good. As it is, we sit at home. Piotr listens to music; we cook. Going to the store and for short walks are the highlights of the week, but each time we go out, I worry that Piotr will touch someone, get too close. It's not really about the virus — I just don't know how people would react to his behavior. Everybody is so scared these days. We are supposed to keep a distance of 2 meters (6.5 feet) between people at all times, even when walking on a sidewalk. There are lots of rules, but nothing specific for people with autism. No one thinks about people like Piotr. So he just waits for tomorrow.

Nantes, France - Lise Larrivière, mother of Jessica, 13

I have had to make some tough choices. Although Jessica's therapeutic team does videoconferencing, and they've sent me a program to follow, I have to work. My options were to stop working and not be paid, keep working and let Jessica regress, or let aid workers come to the house. But the workers would have no gloves, no masks, no equipment whatsoever and could bring the virus with them. As crazy as it may seem, I took this third option. There's some good news, though. A few days ago, the government eased some of the lockdown rules for people with autism. It used to be that trips outside were limited to a maximum of 1 kilometer and one hour away. These strict rules were a problem for grocery shopping in particular, because Jessica has a special diet and the local stores do not have all the food she needs. But this afternoon, I'll be able to put her in the car and drive to a store 10 kilometers away.

Pamplona, Spain - Amaya Ariz Argaya, mother of Mario, 12

My son has severe autism, and I don't know how long he can deal with the confinement without going crazy. I also worry that if he does get infected, there is no special hospital admission protocol for children with autism, and that would be a huge issue. But at least we now have a law in Spain permitting people with autism to go for short walks. The problem, though, is what we call the 'balcony police.' Because others are not allowed walks, people throw nasty comments from their balconies or windows at parents strolling with their autistic children. Some families wear blue ribbons on their arms when they go out, to signal to others that they are with someone who has autism. Others refuse to do so because wearing ribbons reminds them of the armbands the Nazi party introduced during World War II. Here, in Pamplona, people on the balconies are not so vocal — probably because our local autism association, Asociación Navarra de Autismo, which I lead, has done many sensitization campaigns over the years. We don't wear ribbons here, but we do wear orange vests with the name of the association on the back, which either the parent or the child can wear. It just makes life easier.

Lisbon, Portugal - Owen, 13

On Wednesday, 11 March, they said they might cancel school. At the time, I thought that would be good, that there would be a lot of advantages of doing school at home. I wouldn't have to ask to go to the bathroom. Teachers wouldn't yell at me or give me detention, and I'd be allowed to drink water during French lessons. I made a list of a lot of things. Then on Thursday, I got an email saying they won't cancel school, and I was upset. But then on Friday, they said they would — starting Monday.

On the first day, it went really well. I did pretty well with my tasks for school. But over the next few days, there were a few tasks that I ended up not doing. Maybe I overslept and missed a lesson, or I didn't do a good job on a lesson and I had to redo it, but I didn't do it right away. The lessons I missed built up and I panicked. Then it was impossible to do any more lessons because I was too focused on the panic. So getting me to do my work is a big problem. And what if this doesn't get

fixed by the summer? Summer holidays are usually the time when I make memories. If I lose my summer holidays, there is no way I am going to get them back.

Dublin, Ireland - Raul Portales, 43

My case has two sides, one as an autistic individual and the other as the father of two autistic girls. The girls are doing quite okay since we swapped the school routine for a very similar one at home and managed to get a tutor to come to our home three days a week. The predictable routine helps everyone. It is hard for us to get outside, but we are well equipped to exercise at home with an indoor swing and a trampoline.

We do miss some things. My older daughter has a very limited diet. Among the few things she eats are McDonald's nuggets and chips, so we used to go to McDonald's every week. Yesterday she said, "I want eat McDonald's." That sort of sentence is very rare for her, and it's the sort of thing we reward. Except that we cannot, and she doesn't understand why. She kept asking; she was on the verge of tears — and this was heartbreaking for me.

As a software engineer, I get to work from home, and my employer has been very supportive. The company has offered its employees flexible hours and time off if they need it, as well as access to caregivers. What I find fascinating is how all the social rules have been rewritten suddenly. I see neurotypical people struggling to adapt, yet I find it quite easy. I have long been adapting to rules that do not make much sense to me, but the new ones have a reason behind them, so it is easier for me to understand why they exist. A lot of my coworkers are missing the chitchat and the small social interactions at the office, and I miss them too, but I got used to the new normal quite easily. I do not need the interaction as much as neurotypical people do.

Manchester, England - Neenaw, 68

I am an older person with a very late diagnosis of autism, at age 67, last year. I'm still struggling to understand how I've survived all these years. The pandemic has greatly increased my anxiety, with which I've been plagued all my life. I was scheduled for counseling, which, of course, hasn't been possible. (I got a letter asking me to book some phone sessions — but I'm phone phobic.) To survive, I'm having to employ all the coping strategies I have learned over the years. These include living one day at a time, trying to keep busy — I'm always trying to declutter the house, but it's difficult — and staying off social media. Still, I spend a lot of time in bed, unable to do much. I do arts and crafts when I can. I watch TV and Netflix, but I get bored easily. I'm bad tempered because of the lack of compliance from much of the general public and because I don't have much confidence in the government. I'm very emotional about all those going above and beyond, and immensely proud of them.

I'm agoraphobic — I fear crowded places — and struggle with social situations at the best of times, so lockdown isn't a big deal, but I'm scared of delivery people bringing the virus. I'm chronically ill and disabled and come under the government's 'extremely vulnerable' label, which makes me really scared. We have a basket on our porch for deliveries and signs in the windows explaining our situation, and we spray everything with isopropyl alcohol. I'm washing my hands excessively and had to order extra hand cream. I get suicidal at times, but knowing what a nightmare that would be for my family, I have been able to fight the feeling. Pervasive thoughts are like a swarm of wasps in my head, but I'm winning. As I said, one day at a time.

Birmingham, England - Sam Ellis, 15

Before the coronavirus pandemic, I was preparing for exams, which have all been cancelled. Since the closing of schools, I've had all routine ripped away from me, and I'm struggling to make a fixed routine for myself. On the other hand, having a sudden abundance of free time has allowed me to develop new skills and hobbies. Before the pandemic, I didn't get much spare time to write stories and poems, which I really enjoy as it relaxes me and allows me to get my ideas out. But in the past two weeks, I've got loads done! I've also had time to develop my drawing skills. Not having to worry about exams is a godsend, too. The stress being lifted from me has done wonders for my mental health.

What is it like to be an autistic person where I live? Well, for one thing, the streets are much

quieter, so going out for a bit of a walk isn't so daunting anymore, although there are more people than usual on the streets. Being allowed to avoid getting too close to people is also something I didn't know I'd appreciate until now! I do miss the familiarity of seeing my friends each day, however. I'm taking each day as it comes, making small plans here and there. Some days, I get into a slump. Other days, I get loads of stuff done. But most days, I usually sit somewhere in the middle. It's important to remember to do what makes us happy, to find calm in this storm. Allowing time to rest and enjoy various activities is vital, especially with the stress of the ever-changing situation.

New Hampshire, United States - Samantha Theriault, 27

Before COVID-19, I worked two part-time jobs — one in my professional field (museums) that has always been remote, and the other at the front desk of an ice rink. I took it so I could get out of the house, talk to people about my interests and be part of my community. Now the ice rink is closed, and I have filed for unemployment. I miss the routine of going there and talking to my coworkers, skaters and their families the most. I am struggling emotionally because this part of my life is suddenly cancelled.

My fiancé is working remotely. I am grateful he still has a job, but we are getting on each other's nerves at times. Desk space was an issue: I see our home computer area as my office, so we set up a second office area in another room so we wouldn't be bothering each other.

Another one of my concerns is someone in my family getting COVID-19. It took multiple family members (including myself) calling my grandparents daily for weeks before they understood why they couldn't go out to the stores. That was a frustrating ordeal. My mom is a healthcare worker — she has a superhero job. I'm worried about her getting it, the decisions she and her staff will have to make and the stress they'll be under. I'm worried about losing family members and friends, and how drastically my life could change if that happens. I hate that it feels like choosing between life and death if you need to get groceries or want to pick up a bottle of wine. My anxiety makes it very, very difficult to focus and be productive, which I am worried will impact me professionally, on top of everything else.

29 April update: My life has settled into a new normal. I feel a bit less anxious, instead moving into boredom and burnout. I'm still trying desperately to be productive, and playing a bit too much "Animal Crossing."

Edinburgh, Scotland - Bryony Hockin, 26

On 25 February, when the U.K. had four confirmed cases of COVID-19, I was on a train from Edinburgh to visit friends in London, a belated birthday celebration. At the train station, I grabbed a travel-size bottle of hand-sanitizer, enough for my long weekend, unaware that this would be my only supply for the next several months.

The next day, I met my mum for lunch and gently chided her for ignoring my advice not to come, since she had just recovered from pneumonia. I spent the next hour quietly reminding her to stop touching her face. When I was a kid, I had all kinds of habits and stims (my favorite was chewing my hair), and rather than scold me, my mum would just quietly point it out to me and ask if I realized I was doing it. It felt very strange to reverse the positions 20 years later.

Like many autistic people, I have a strong sense of right and wrong, and this has caused some conflict with friends and relatives who haven't taken social distancing seriously. On 15 March, I had a row with a friend who refused to start social distancing until the government explicitly told her to do so. I'd read about Patient 31 in South Korea and was horrified that one woman had infected thousands of people. The thought that someone I considered a friend was willing to risk doing so because she felt that attending a cocktail night was "essential to her mental health" was infuriating. When I developed flu-like symptoms that same day, I self-isolated for a week.

Since lockdown began, I've been mostly unable to function and endlessly tired, as so many of my routines have been destroyed or disrupted. I suspended all work on my thesis. (I am a Ph.D. student studying chemistry.) All the grocery stores near me have been, until recently, mostly empty due to panic-buying. I always keep a small stockpile of my 'safe foods,' but it didn't last long. I've struggled to adjust to phone and video calls for work, due to auditory-processing problems. I had a meltdown after calling the doctor's office and learning that they only had phone appointments available.

Neurotypicals are, for the first time, experiencing the overwhelming fear of uncertainty that I experience every day. The unanswered questions. Not knowing who to believe. Going outside now requires a checklist, a plan of action, a script and a ritual, something I've done since I was old enough to walk.

Brisbane, Australia - David, 11

Coronavirus ruined a great year for me. I had a great teacher, good friends in my class. But I'm fine. I just go, okay, we are doing this now. I usually like being at home anyway, unless Mum and Dad say it is a compulsory outing. What changed is that school is over Zoom. The teacher is not staying with us through much of the day. She usually checks in with the class in the morning and then we just do the work we've been assigned. I have a lot more free time now. In normal school, I learn mostly social stuff, and now at home I'm catching up on academics. Since I can't go out unless it is to exercise, I end up exercising more. We even bike with our cats, which ride in carriers strapped to our backs. I'm not worried much about the virus itself. I trust Mum and Dad to give me updates when the situation changes, like if there is a cure or if things are getting worse. All in all, I think it could be a really good bonding experience for the world to work together. Together, we can get through this.